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ABSTRACT

This report evaluates how effective the brokerage system operated by the Community Living Society in Vancouver (British Columbia) has been in meeting the needs of individuals with a mental handicap living in the community. The program stresses service brokerage, a mechanism to deliver the planning resources required to arrange and purchase community services, and individualized funding, under which individuals receive funding directly or have status in determining how funding will be spent on their behalf. Chapter 1 presents a framework for evaluation and identifies the decision-making criteria used in the study involving 20 interviews. Chapters 2 through 6 examine the impact that service brokerage and individualized funding have had in terms of each of these criteria. Accordingly, Chapter 2 examines access to planning resources; Chapter 3, access to funding according to individual need; Chapter 4, accountability to individuals in decision-making; Chapter 5, the range of alternatives for community-based services; and Chapter 6, securing the status of individuals' close family and friends in the decision-making process. Chapter 7 assesses the applicability of service brokerage and individualized funding to other groups, and Chapter 8 outlines conclusions. Among appendixes are details of the study methodology and an article, "Individualized Funding in Relation to the Canada Assistance Plan," by Sherri Torjman. Includes 37 references. (DB)

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The POWER to Choose

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An Examination of Service Brokerage and Individualized Funding as Implemented by the Community Living Society

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The Power to Choose

An Examination of Service Brokerage and Individualized Funding as implemented by The Community Living Society

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The G. Allan Roeher Institute
Kinsmen Building, York University, 4700 Keele Street,
North York, Ontario, Canada M3J 1P3 (416) 661-9611

Institute Director & Project Director:	Marcia H. Rioux
Principal Researcher:	Michael Bach
Researchers/Advisors:	Melody Hessing Suzanne Peters
Editors:	Laura Code Giovanna Heffernan
Desktop Publishing:	Victor Salus

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Kinsmen Building, York University, 4700 Keele Street,
North York, Ontario, Canada M3J 1P3 (416) 661-9611

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FOREWORD

Entering the 1990s we find ourselves at an exciting time in Canada for those people who have traditionally been disadvantaged because of being labelled mentally handicapped. The 1970s found us adopting a new philosophy of "normalization". That concept argued that people with a mental handicap ought to live in a way that was as close to how others lived as possible. That resulted in the 1980s in a re-thinking of the appropriateness of segregated settings — of institutions, of separate schools and classrooms, and of many of the therapeutic programs in place.

During the 1980s a number of events occurred that are beginning to have a significant impact on those who have a mental handicap. In 1985 the Equality Rights provisions of the Canadian Charter of Rights and Freedoms came into effect. These provisions specifically guarantee the rights of those who have a mental handicap along with the rights of many other disadvantaged groups. As well, during this decade, the federal and provincial Human Rights Acts added mental handicap to the list of groups against whom discrimination was prohibited in employment and in the provision of services, facilities and accommodation.

The province of New Brunswick passed an amendment to the Schools Act in 1986 that entitled all children, including those with a mental handicap, to attend their neighbourhood schools in classrooms with their age peers. Across the country were found enlightened individual school boards opening their classroom doors to those with even the most severe disabilities. Even entrance to post-secondary education facilities is being experimented with in several places. For instance, in Alberta, a university has made its facilities available to a number of students with a mental handicap, and a community college in Ontario has welcomed a number of students with a mental handicap who, until this program was developed, would not have been able to even contemplate such an educational opportunity.

In Nova Scotia, an innovative respite care program has been created for a little boy whose only alternative would have been to live his life in an institutionalized hospital setting. Creative supported work projects are springing up in a number of communities. One program in Newfoundland was given an award for its inventiveness in finding real jobs at real wages for persons with a mental handicap who might otherwise never have known the rewards of being employed.

Many provinces have established policies that promise the closure of their institutions, recognizing that only if people are in their own communities can there be any expectation that they can lead fulfilling, healthy and satisfying lives.

Lest this all sound like naive optimism, there are a number of chilling realities which we still face. Over 20,000 individuals with a mental handicap remain in large institutions in Canada and most of the governments have still not committed the necessary funds to assist with their deinstitutionalization policies. The vast majority of our citizens with a mental handicap live on incomes that are well below the poverty line and come nowhere near meeting their needs. Most adults with a mental handicap still work in segregated work environments at wages well below the minimum wage guarantees, despite Charter guarantees, Human Rights laws and employment equity programs. Government income assistance programs continue to provide money to individuals in a way that disentitles them from making their own choices about how and where they want to live, work, and spend their leisure time. Families are still forced to give up members of the family who are handicapped to the care of the state for lack of alternative supports.

In some cases, this is because old patterns are hard to break. Professionals are sometimes committed to traditional notions of treatment and therapy. Governments that have tinkered with programs and policies are timid about overhauling systems. The legal system does not know how to argue for the rights of those with a mental handicap. Parents have fears about their children's future and security. People with a mental handicap are only beginning to learn to demand their rights and express their needs.

The government of British Columbia was one of the first provincial governments to decide to close its large institutions. In deciding to do that, one of the routes it chose was to try something radically different from the conventional means of funding group homes and other services. With pressure from a group of parents, they decided to think much more broadly about what the needs of people with a mental handicap meant as they left the institutional environments. Together with the families they defined needs as more than a roof over their heads and adequate food and minimal comforts of life. They defined needs as the ability for individuals to make their own decisions, to have some means of determining for themselves how and where they wanted to live, and to control their funding in order to do that. This was radical and visionary. It foresaw some of the political events and initiatives that came later. The model of service that was put in place to enable people to have control over their own resources and to have a mechanism in place to ensure they would participate in the choices about their lives in the community was called *service brokerage*.

This study evaluates how effective the brokerage system operated by the Community Living Society in Vancouver has been in meeting its goals and in meeting the needs that individuals with a mental handicap have as they attempt to live as full participants in the community. In some ways, service brokerage can be said to be very successful; in other ways, it has not been so successful. It has had to operate within a traditional social service and income assistance framework that, to date, has proven itself unable to provide the necessary support for its full implementation. The model has, however, shown us that we need not fear fundamental change. Instead, it challenges us to keep trying, to keep working towards real involvement in society for people with a mental handicap. It is a system that does not stop at trying to improve services, but moves beyond that to equality, to self-determination, to dignity, to citizenship. We are no longer searching for answers concerning services but concerning the empowerment of people who have been labelled. These are the issues that concern people involved in other disadvantaged groups. These are also the issues that service brokerage set out to address.

Canadian society set itself a goal in adopting the Canadian Charter of Rights and Freedoms. This goal involves accommodating the differences of people. It means establishing programs and policies that support individuals to become contributing members of society and to feel that they belong. The government of British Columbia, and the originators and implementers of the idea of service brokerage effected through a community board, deserve to be recognized for their efforts. It is a process; a system that responds to those it serves. People in Canada and around the world watch with interest as it evolves. While the philosophy on which it is based is fixed, the mechanisms and means for ensuring that those goals are met continue to be flexible and to change. We hope that this evaluation is helpful to others — to governments, service providers, families, and those who live with a mental handicap — in providing the incentive to deinstitutionalize in a manner that ensures equality, dignity and self-determination.

The G. Allan Roeher Institute decided to undertake this evaluation because it falls within our mandate to examine ways and means in which social policy can be effected to improve the lives of people with disabilities. This model of service delivery has a number of major implications for the way that service is being provided at present. First, it is dependent on individualized funding, which in itself has implications for the delivery of social assistance and other disability income programs. There is an appendix to the study which outlines what this means with respect to these funding policies. I also recommend two other publications of The Institute, *Income Insecurity* and *Poor Places,* for more information about the income supports, and their implications, that are in place for persons with disabilities.

Second, this model shifts the control of service delivery from the service provider to the individual being served. This has important implications for rationalizing the whole field of service delivery and the delivery of income-in-kind benefits. It has the potential to end the critical and well-recognized problems of providing either more service than an individual needs or less service than an individual needs because of the way service provision is made available.

There were several other reasons for undertaking this study. Most studies of quality of life tend to use indicators that measure factors around standard of living and satisfaction levels. Some tell us, for instance, whether people have proper diets, whether there are adequate fire and health measures, whether they have access to transportation, and whether or not the options fall within acceptable norms. Others look at individuals' subjective states, and attempt to measure things like personal happiness. What both have failed to measure is what most people with disabilities consider most critical to their well-being; that is, how much control they have over their own lives. In most cases, individuals are not as worried about their standard of living as they are about whether they have been able to choose what they have and what they do. This study provided us with an opportunity to develop measures that would enable evaluation of quality of life from this perspective. We hope that this research methodology will be built upon by others.

Finally, we undertook this study because we were receiving inquiries about service brokerage from people within the disability movement not only in Canada but also in the United States, England, Australia, and New Zealand. We also had inquiries from a number of government departments about brokerage for people with a mental handicap. We were asked as well to give our views on whether service brokerage might be helpful to other populations such as older persons who needed supports, people with physical disabilities and people with psychiatric disabilities. We have, therefore, included a brief analysis of the applicability of this model to other sectors of the population.

Discussion and debate about this model have become widespread. I think it is a healthy discussion and I look forward to the continuing efforts of families, those with a mental handicap, policymakers, and service providers to enable greater participation of individuals in their communities in a manner that recognizes their equality and their citizenship.

I would like to thank many people for their assistance in this study. First, I would like to thank a number of people who acted as researchers and advisors on the project including Michael Bach, Dr. Suzanne Peters, Dr. Melody Hessing, Sherri Torjman, Cameron Crawford, Diane Richler, and Melanie Panitch.

I would also like to thank the Disabled Persons Unit, Health and Welfare Canada and the Disabled Persons Secretariat, Secretary of State Canada for their financial support of the project. In particular I would like to thank Peter Lawless and Sue Potter for their contribution to the consultations held during the project. Of course, the analysis, opinions and conclusions expressed in this report do not represent the policies of the Department of National Health and Welfare.

I would like to thank the Executive Director and the staff of the Community Living Society who provided all information that was requested without hesitation. It is always a difficult job to be evaluated since the bad is discovered along with the good. But the CLS was open and anxious for the evaluation to be undertaken, and co-operated to the extent that at times, I am sure, resulted in disruptions in their own operations to accommodate our work.

I would also like to thank the government officials and bureaucrats who gave freely of their time and provided a substantial amount of information for the evaluation.

Finally, I would like to thank most sincerely the families and the individuals with a mental handicap who participated in the study. They use the service brokerage model and so were really the only ones who could tell whether it worked for them or not. In the end they have the last say on whether we, as a society, are meeting their needs.

Marcia H. Rioux
Director

INTRODUCTION

This report is about the impact of service brokerage and individualized funding on achieving the aim of self-determination, autonomy, and dignity for individuals with a mental handicap. The report is based on a study of the Community Living Society (CLS), a non-profit, community-based agency that operates in Vancouver, British Columbia. The CLS has implemented service brokerage and individualized funding as the means to achieve the goal of self-determination, autonomy, and dignity for the individuals it serves. The organization has provided a setting in which to carry out a number of interviews with individuals, families, support staff, service brokers, and the CLS administration, about the impacts of service brokerage and individualized funding. Some government officials and representatives of other service agencies were also interviewed.

Service brokerage is a mechanism to deliver the planning resources that individuals require to arrange and purchase community supports and services. Service brokers assist individuals and their families in defining needs, provide information about alternative support and service options, identify potential service providers, assist in arranging agreements for service delivery, and provide consultation to individuals and service providers where requested. The underlying principle of service brokerage is to enable the individual, through the provision of information and planning assistance, to determine as fully as possible the decisions affecting his or her life.

While it has not been fully implemented, the Community Living Society has developed a particular model for service brokerage. In this model, service brokers are to be employed by and made responsible to an "autonomous fixed point of response". The fixed point of response is to be a place in the community where individuals and families can go for information and planning assistance in arranging community supports and services; a place that is autonomous from both funding agencies and service providers. It is to be represented by a community-based, duly elected board. In the CLS model, a service broker is an individual's "agent", autonomous from agents of the government who allocate funding for community supports and services and from direct service providers. Service brokers are to be accountable to the community board which represents the fixed point. The term "fixed point service brokerage" is sometimes used in this report to refer to service brokerage which is attached to an autonomous fixed point of response.

Individualized funding is a mechanism to deliver the financial resources required by individuals to purchase goods and services to meet their basic and disability-related needs. In British Columbia, individuals with a mental handicap are entitled to income assistance, based on financial circumstances, to meet their basic needs. Additional funding may be allocated on a discretionary basis to purchase goods and services required because of an individual's disabling condition. These goods and services may include housing, attendant care at home or at work, special training programs, technical devices, etc.

Individualized funding is different from other funding mechanisms in that individuals receive funding directly or have status in determining how funding will be spent on their behalf. Through an individualized funding approach, costs are calculated in relation to the goods and services that a particular individual requires. Funding is allocated on the basis of a statement of his or her needs and the costs of meeting these needs. Under individualized funding, cash may be provided directly to the individual, or via a third party, to purchase goods and services. Alternatively, government may act as the purchaser-of-service. Purchases are made on the basis of purchase-of-service agreements in which individuals have contractual status. The distinctive feature of individualized funding is the status provided to an individual to determine the conditions on which services will be purchased and delivered.

The Community Living Society was incorporated in 1978. In the same year it entered into an agreement with the provincial Minister of Human Resources to deliver service brokerage and to manage individualized funding.

The constitution and bylaws of the CLS provide for an elected community board. Board members include parents and others who are drawn from various sectors in the community. The Board is responsible for two major functions. First, it is to act as a "fixed point of response". In this capacity the Board provides a range of services: service brokerage delivered through three service brokers; management of individualized funding through financial accounting and tracking of the funding an individual receives; expertise in development of community resources; and staff training.

Second, the Board is responsible for delivery of residential and vocational services funded by the provincial government. Delivery of these services is funded through agreements with the B.C. Ministry of Social Services and Housing (previously the Ministry of Human Resources) and the B.C. Ministry of Health. The CLS now manages one of the largest service agencies in British Columbia for delivering supports to people with a mental handicap. It provides supports to thirty homes where three to four individuals live, and provides vocational day supports to approximately 100 individuals. This latter program is referred to by the CLS as the "day module" or "day mod".

The Board employs an executive director who manages the day-to-day operations both of residential and vocational service delivery, and of service brokerage, as well as various support staff for these functions. (See organizational chart of the CLS in Appendix B.)

Fixed point service brokerage and individualized funding have been only partially implemented for the majority of individuals served by the CLS. They have been fully implemented for a few individuals. This is due to a number of factors which are discussed in an historical analysis provided in Appendix E. An overview of this analysis is provided below.

The CLS was formed through the efforts of the Woodlands Parents Group. This group was initiated in 1976 by a few of the parents who had sons or daughters living in the Woodlands School, an institution for people with a mental handicap in New Westminster, B.C. The Woodlands Parents Group submitted a proposal to the B.C. government in 1977 that outlined alternatives to institutional care, and articulated principles of individualized funding and service brokerage. The proposal recommended that the Community Living Society be formed and mandated to provide planning assistance to individuals and families through "community service agents" or service brokers. This proposal became the basis for a policy initiative in British Columbia, known as "Project LIFE", to move individuals with a mental handicap from institutions to the community.

The Minister of Human Resources introduced Project LIFE in 1977. One of the commitments made by the government under the Project was to provide funding for community services at the same level as had been previously allocated for institutional care. As part of Project LIFE, the minister also agreed to provide core funding to the CLS to deliver service brokerage and to manage individualized funding.[1] Since 1978, the B.C. government has continued to provide an annual grant for service brokerage.

The agreement between the CLS and the government outlined specific provisions for individualized funding. It stipulated that funding was to be attached to a General Service Plan (GSP) prepared with the assistance of a service broker and signed by the individual. Each individual was to have a GSP that would function as a contract between the government and the individual, and outline the general parameters of the individual's funding. Individual Program Plans (IPPs) were in turn to become contracts between individuals and service providers. Prepared with the service broker and based on the General Service Plan, IPPs were to be used to contract for specific services outlined in the plan. These arrangements, however, were never fully implemented.

In 1980, the CLS began delivering residential services as a direct service agency. This was a significant departure from its original intention to maintain an autonomous relationship between service brokerage and the service system. It was also a departure from the arrangements for individualized funding in which the GSP was to be the basis of funding allocations and contracting for service delivery.

A number of factors led to the decision to begin delivering services. Many individuals who had moved to the community after 1978 with the assistance of the CLS were living in inadequate and unacceptable living conditions. The funding for the CLS was depleted, the anticipated funding under Project LIFE had not materialized, and the ministry was reluctant to have additional individuals move to the community until arrangements could be secured for those already living in the community and supported through the CLS. As well, community service providers were not generally willing to recognize the GSP, prepared by service brokers, as the contractual basis for purchase and delivery of services.

Consequently, most were reluctant, and some refused, to acknowledge the role of the broker as the individual's agent. Nor did the ministry require that GSPs become the basis of contractual arrangements, or that brokers be recognized as individuals' agents. Barriers to implementation of fixed point service brokerage and individualized funding persisted after 1980.

As part of its deinstitutionalization initiative, the provincial government decided in 1983 to close Tranquille, an institution in Kamloops, B.C. Procedures were established to manage the closure over an eighteen-month period. This involved a "decentralized" strategy which attached the planning mechanism to regional offices of the Ministry and to local associations affiliated with BCMHP (British Columbians for Mentally Handicapped People, now BCACL: British Columbia Association for Community Living). The general strategy of the ministry was to select service providers through a tendering process. Requests to provide residential and vocational support to groups of individuals living in Tranquille were put out to tender. This approach fundamentally contradicted the principles of individualized funding and planning through an autonomous, community-based planning agency or fixed point of response. The CLS was, however, contracted by the ministry to provide service brokerage for twenty-five individuals leaving Tranquille.

In 1986, the Ministry of Social Services and Housing began to close wards in another institution, the Woodlands School. The delivery mechanism for planning resources was more highly centralized within the ministry for this downsizing process than had been the case with the closure of Tranquille. Tendering procedures were again implemented. Under these procedures, prospective service providers prepared proposals on the basis of "non-identifying profiles" of individuals prepared by ministry social workers and Woodlands staff. Again, this approach differed substantially from service brokerage and individualized funding.

Another development in 1986 was the establishment of the "Services to the Handicapped" Division within the B.C. Ministry of Health. The goal of this division is to fund and arrange for delivery of community services in order that individuals living in extended care facilities can be supported in the community. This division has, to some extent, employed the mechanisms of service brokerage and individualized funding in order to achieve this goal.

The reorganization of the Ministry of Social Services and Housing (MSSH) in 1988 was another significant development for the implementation of service brokerage and individualized funding. It resulted in the creation of an operational unit titled "Services to the Handicapped" in area offices of the ministry, and reinforced the ministry's role in delivering planning resources to be used in arranging community supports. In this sense, the reorganization reflected a substantial break with the principles of the autonomous, community-based, service brokerage that had been the basis of the original agreement between the CLS and the MSSH under Project LIFE.

The following chapter will describe the framework for evaluating the effectiveness of service brokerage and individualized funding. It identifies the five criteria for decision-making opportunity used in the study. Chapters Two through Six examine the impact that service brokerage and individualized funding have had in terms of each of these criteria. Accordingly, Chapter Two examines access to planning resources; Chapter Three access to funding according to individual need; Chapter Four accountability to individuals in decision-making; Chapter Five the range of alternatives for community-based services; and Chapter Six securing recognition of and status for individuals' close family and friends in the decision-making process.

Chapter Seven assesses the applicability of service brokerage and individualized funding to other groups including individuals with a physical disability, individuals with a psychiatric disability, and individuals who are elderly.

Chapter Eight outlines conclusions to the study.

This report includes a number of substantive appendices. Appendix A discusses the methodology for the study. Appendix B provides an organizational chart of the Community Living Society. Appendix C describes the procedures implemented by the CLS for costing the General Service Plan. Appendix D examines the feasibility of an individualized funding approach under the provisions of the Canada Assistance Plan and Established Programs Financing. Finally, Appendix E provides a more detailed historical analysis of the implementation of service brokerage and individualized funding by the Community Living Society.

Notes

[1] British Columbia, Ministry of Social Services and Housing, *Agreement between the Community Living Society and The Minister of Human Resources*, September 8, 1978.

CHAPTER 1

THE FRAMEWORK FOR EVALUATION

This chapter describes the evaluative framework used in this study to examine the impact of service brokerage and individualized funding. The framework was developed through a number of steps.

The first step was to select the goal against which the effectiveness of service brokerage and individualized funding would be measured. The stated goal of the Community Living Society — to achieve self-determination, autonomy, and dignity for individuals with a mental handicap — was selected for this purpose.

The second step was to develop a measure which would be used to assess the achievement of this goal. The extent to which individuals and/or their families had the opportunity to make their own decisions was selected as the measure of self-determination, autonomy, and dignity. Individuals and families who were interviewed identified three kinds of decisions that they wanted to be able to make: (1) the nature of supports an individual would receive; (2) the service providers who would deliver supports; and (3) decisions affecting the individual in ongoing service delivery. The meaning and importance of these decisions to individuals and families are discussed below.

The third step was to identify the procedures, established through service brokerage, individualized funding, and other planning and funding mechanisms, that have been used to make these decisions.

The fourth step in developing the framework was to select the specific criteria of *decision-making opportunity* that would be used to assess the impacts of the mechanisms of service brokerage and individualized funding.

Each of these steps is discussed in more detail below.

THE GOAL OF SELF-DETERMINATION, AUTONOMY, AND DIGNITY

The selection of the goal of the CLS as the basis for the evaluation was made in preliminary meetings on the research. Participants in these meetings included the research team, a selection of parents whose sons and daughters have been served by the CLS, CLS Board members, staff, service brokers, and a representative for the funders of the research.

The CLS states two sources for its goal. First, it is based on the "beliefs and values" which were articulated by the Woodlands Parents Group, and which continue to be a foundation for the CLS. The CLS states these beliefs and values as follows:

> WE BELIEVE THAT EACH PERSON is a unique individual, having worth, no matter what the degree of handicap.
>
> WE BELIEVE THAT EACH PERSON has the right to live a life of dignity.
>
> WE BELIEVE THAT EACH PERSON must have their personal autonomy protected at all times and every effort must be made to nurture the development of self-determination for the individual.
>
> WE BELIEVE THAT EACH PERSON should have the opportunity to live as a full member of society in his or her own community.[1]

Second, the CLS states that self-determination, autonomy, and dignity also reflect fundamental freedoms, legal rights, and equality rights under the *Canadian Charter of Rights and Freedoms*. The organization states a commitment to ensuring that these freedoms and rights are fully enjoyed by individuals with a mental handicap.[2] The CLS has implemented service brokerage and individualized funding as the means to achieve its goal.

This research began with the assumption that "self-determination, autonomy, and dignity" could be measured as an "outcome" in individuals' lives. Further, it was assumed that this outcome could be related in some "causal" way (negatively and/or positively) to the mechanisms of service brokerage and individualized funding. These assumptions were grounded in the recognition that within the field of mental handicap, quality of life outcomes like "self-determination, autonomy, and dignity" have been identified as a basis for evaluating policies and programs. In a seminal review article on deinstitutionalization and evaluation research in this field, Emerson suggests that measures of "community participation or exclusion, power, and autonomy" are required to adequately evaluate quality of life outcomes for individuals.[3] Mitler suggests that one of the important criteria for judging the quality of life of individuals with a mental handicap is whether they have "opportunities to express choice not only in clothes and food but also in their choice of where they are to live, the kind of schools they go to, the kinds of work that they would like to do, the way they spend their leisure ... their social and sexual relationships."[4]

While there has been a growing commitment to evaluating quality of life using outcomes related to self-determination, autonomy, and dignity, there is little quality of life research undertaken on these terms. There have been some studies which focus on "decision making" within a residential setting. Bercovici, for instance, found in an evaluation of residential programs "that opportunities for decision making and choice making were generally absent from the daily routines."[5] In another study, Kishi, et al. found that individuals with a mental handicap were much less likely to have opportunities to make daily decisions about meals, leisure activities, and relationships with friends and families, than individuals without a handicap.[6]

However, measures and criteria to examine the wider array of choices, implied by the goal of self-determination, autonomy, and dignity, have not been developed. Developing the measure of self-determination, autonomy, and dignity, and specific criteria for evaluation, was the methodological challenge of this study.

DECISION-MAKING OPPORTUNITY

For the purposes of this study, *decision-making opportunity* was selected as the measure of self-determination, autonomy, and dignity. For the CLS, self-determination, autonomy, and dignity are achieved in large part when individuals have the opportunity to make the whole range of personal decisions, from the direction their lives will take, to the "who, what, where, and how" of the supports and services they receive, to daily decisions about clothing, meals, and leisure. Individuals, families, and others who were interviewed also wanted individuals to have opportunities to make decisions about where to live; who to live with; the kinds of friends and relationships that would be sought and maintained; the kind of education, employment, and daily activities that would be pursued; the leisure and recreation activities that would be enjoyed; the medical treatments and health care they received.

For the purposes of this study, this wide array of decisions was organized into three categories or areas of decision making. As identified above, these include:

- decisions about the nature of community supports to be used;

- decisions about which service providers would be used to deliver the supports;

- decisions in ongoing service delivery.

Many of those who were interviewed felt that they had, at various times, been denied the opportunity to make these kinds of decisions. Common in the perception of many was that these decisions had been made by others, whether government officials, social workers, service providers, support workers, doctors, or other professionals.

The following sections describe the barriers to decision-making opportunity that individuals and families experienced prior to their receiving service brokerage and/or individualized funding.

DECIDING THE NATURE OF COMMUNITY SUPPORTS

The decision that an individual was to move into institutional care, or move from the institution to the community was of major significance for the individuals and families interviewed for this study. In making such a decision, individuals' needs for support were being redefined. New choices were being made about the supports required to secure individual welfare and well-being. These supports often included the kinds of residential, employment, recreational, and educational arrangements that were considered best able to meet an individual's needs.

However, many of the individuals and families who were interviewed felt that, in the past, the decisions about the kinds of supports they were to receive had been made by others. One individual, who was a participant in this study, lived for over thirty years in institutions in British Columbia, including the Woodlands School in New Westminster. Margie first lived in an institution when she was twelve years old. She was placed in institutional care because many people, including her father, felt that there were no other options. Over the thirty years she lived in institutional facilities this perception became shared by others, and was very slow in changing.

> *I was only twelve ... My doctor had given me some medication when I first started taking seizures. I was gettin' foggy. Like I would listen to the radio, get comfortable, and I'm asleep. I said to Mom, "God, I feel terrible, I know it's the medication". And then I started gettin' worse, hearing voices that weren't even there. Sometimes I'd be seeing something that wasn't even there ... that was the side-effects of the medication ... And so I wound up in Riverview [hospital]. I went home in a month and before I knew it I was right back there. To my dad I had a nervous breakdown, but it was the wrong ones [the medication]. So I had one struggle ... I thought I could get somethin' going in my dad's head that [the institution] was no place for a young girl, she was to be home. That didn't ring a bell in my dad's head at all. Not until he was sick and dying, I was twenty-nine then, was he sorry he never took me home when I asked him ... I have had one life I would not want somebody to go through themself. I been battered around, pushed around, lived in different institutions for thirty-two years ...*
>
> *I was determined to get out ... For thirty-two years I had no parties, no nothin'. I wanted no more of people tellin' me where to go, when to eat, I made up my mind ... My social worker thought I was nuts for wanting to move out because I had everything there. "You don't see it my way, do you?" I said. She said, "No."*

Margie's frustration was that for "thirty-two years" she could never get anyone, with the exception of her mother, to "see it her way".

To place an individual in institutional care was usually not the choice that individuals or families hoped for or wanted. Many, however, had been told by doctors, social workers, or other professionals that no other options could be found for in-home supports, or other adequate community arrangements. The institution was seen as the only source of security for the individual. And in many cases families felt that this was their only option for relief from sole responsibility for care.

A few parents who were interviewed also indicated that until very recently they still saw institutional care as the only sure way of meeting their son's or daughter's needs. They felt that institutions provided security and stability for individuals who were otherwise vulnerable in the community. For example, one mother who was interviewed for this study had been extremely concerned when told that her daughter, Sarah, would be moving from the Woodlands facility to the community:

> *My daughter was in a group home when she was young. She was badly abused in it and became very disturbed, so she went to Woodlands. She was not tied to a chair. She was not abused. The staff were very kind and loving. She was quite happy ...*

The account of this mother, like that of other parents who have expressed concern about the closure of institutions, may be more than an argument for institutional care. It may also be interpreted as an indictment of the lack of supports in the community that can respond to their definition of their son's or daughter's needs: a supportive, caring, secure environment. This particular mother had tried, unsuccessfully, to find these supports before her daughter went into Woodlands.

Many who were interviewed had found that although their choice was that an individual should live in the community, the decision to do so was often entirely determined by someone else. For example, Andrew, one individual in this study, had written in 1985 to Grace McCarthy, then B.C. Minister of Human Resources:

> *I am a resident of Pearson Hospital in Vancouver, B.C. I am writing this letter to you because I have a problem and I feel the best person to talk to about it is you. My problem is this: I would like to move into a group home situation, but I am unable to because of the lack of these kinds of facilities in this and other areas of the province. I feel that perhaps you are the only person with the power to help me as you are in the position to make these decisions.*

Six months later, still in Pearson Hospital, his depression had deepened, he had suffered further loss of social and motor skills, and hallucinatory episodes were becoming more frequent. When he was about to be committed for long-term care to a psychiatric ward, his mother was able to convince the Ministry of Health to provide funding for community supports, and arrangements were made with the Community Living Society to deliver service brokerage and residential services.

It took Andrew and his family over ten years to obtain long-term supports in the community. One barrier to securing a community placement was that Andrew was identified as having a "multiple handicap", and that government departmental responsibility for funding was therefore unclear. Because of this lack of clarity, Andrew was forced to spend two of his first eight years living in Sunnyhill Hospital. His parents then brought him home for four years, but after this time, could no longer provide for his emotional and physical needs.

No financial support was forthcoming from the Ministry of Human Resources, so when Andrew went back to the hospital for assessments in 1978, his mother reluctantly conceded that she was unable to bring him back home. The Ministry of Human Resources then agreed to place Andrew in a group home in the community. However, because the home was funded as a service for children, he could only remain until his nineteenth birthday. When he left the home he was again forced by circumstances beyond his control and choice to move back to the hospital.

Anticipating the loss of funding, his mother had begun to look for other arrangements in 1982. Between 1982 and 1986, when Andrew was about to be committed to a psychiatric ward, his mother was still unable to find the funding, information, or service provider that could be used to arrange the community supports she and Andrew were seeking. According to his mother, it was the label of "multiple handicaps", that had been the barrier:

> *He was caught between health and social services funding and no one was taking the responsibility. No one would take him because of his multiple handicaps. His social worker didn't know how to deal with it. The social worker couldn't do a thing.*

Writing in the spring of 1986 to the Deputy Minister of Health, when her son was most desperate to leave the institution and most at risk of being institutionalized in a psychiatric ward, his mother expressed the following:

> *I am writing to ask you for your help regarding our son... I believe that Andrew's recent behaviourial difficulties are directly related to his unhappiness of being in Pearson Hospital. He feels angry, frustrated and often times is aggressive as a result of not being able to have the freedom for such basic things as:*
>
> *a) going to the bathroom at night*
> *b) having a bath more frequently than once per week*
> *c) doing more walking and crawling just to mention a few things ...*
>
> *A couple of weeks after he had improved to some degree he had another [psychotic] relapse. He again tried to "get away" from Pearson and when he had his chair taken away he tried crawling off the ward. This action resulted in him being confined to his bed ...*
>
> *Why can't Andrew be given the chance to live in a group home or residence again, a setting in which he has thrived in the past ... It seems arbitrary and senseless that his happiness be taken away simply because he is now an "adult" instead of a "child."*

Andrew and his mother are similar to many others interviewed during this research in that they wanted to be able to make their own decisions about the residential, vocational, and other supports that would enable individuals to live in the community. As well, they wanted individuals to have the opportunity to choose the goals they would pursue, and the directions their life would take. They wanted some control, therefore, over how individual needs for support would be defined.

CHOOSING SERVICE PROVIDERS

Some of those who were interviewed indicated that once individual needs for community supports were defined, they also wanted to be able to make decisions about the service providers who would deliver supports. One woman who was interviewed, and who took this position, has a daughter, Christine, who has a progressively degenerative, neurological disorder. When her respite program was cut, Christine's mother came to the conclusion that governments should make commitments to individuals, not to "programs" or "service providers". She wanted the resources and status to choose the service providers who would support Christine.

When Christine's respite care program was cut and then temporarily reinstated at Sunnyhill Hospital, her mother wrote to the Premier of British Columbia, William Vander Zalm:

> *... For the past six years, Christine has been receiving respite care at Sunnyhill Hospital for Children, with plans for long term care. At present, we have been told that any long term care or respite care is an impossibility due to:*
>
> *(a) lack of beds*
> *(b) too long a waiting list*
> *(c) lack of placement for youths over 18 years, who should no longer be at Sunnyhill*
> *(d) cut backs*
> *(e) hospital is over budget.*
>
> *... the only future facility for long term care we've been informed of is Queen Alexander hospital on Vancouver Island ...*
>
> *To suggest that Christine be sent to another hospital is like putting "another nail in her coffin". Christine is familiar with the layout at Sunnyhill, the routine and the staff there. Most important of all, they are familiar with her needs physically and mentally and spiritually. To take this away from her would only hasten her already short prognosis. It would also make it impossible for us to visit and would definitely make it difficult to have her home on weekends ...*

The Premier wrote back with assurances that Christine would receive respite care as long as her family continued to provide care at home. It was also implied that Christine's long-term care needs would be met. The Ministry of Health was then involved to begin planning for Christine's long-term supports. In response to a request by Christine's mother, funding was allocated directly to Christine. The ministry also made available the planning assistance of a service broker through a contract with the Community Living Society. The broker identified potential community resources, and conditions for service delivery were negotiated between Christine's mother and the Ministry of Health. Christine's mother and her family were then able to choose the service provider that seemed most appropriate.

In the view of some of those who were interviewed, the choice of support should be a decision that is independent of the choice of service provider. They wanted first to be able to decide the kinds of support they wanted and needed. On that basis they then wanted to be able to choose the service provider who could best deliver the supports.

MAKING DECISIONS IN ONGOING SERVICE DELIVERY

Parents and support staff interviewed in this study indicated that they did not want absolute "control" over the decisions that were made in ongoing service delivery. More important to them was to ensure that decisions were made in ways that: respected an individual's autonomy; acknowledged the roles of families; maximized opportunities for individuals to choose risks; minimized threats to fundamental health and well-being; and maximized individual potential. Making the "right" decisions in the "right" way was as important when choosing daily activities as it was when choosing a new place of residence, or an educational program.

Like individuals and families, support staff experienced difficult dilemmas around making decisions. For instance, conflicts arose over autonomy or an individual's right to choose risks, and his or her protection and health. Conflicts also arose over individual autonomy and what, from the perspective of support staff, seemed best able to promote personal development. As well, conflicts arose over an individual's autonomy when his or her actions conflicted with the autonomy of other individuals with whom the person lived. For those who were interviewed, the challenge in ongoing service delivery was not in deciding which decisions were most important to an individual's "self-determination, autonomy, and dignity". Rather, the challenge lay in balancing interests and conflicting principles in making any decision, regardless of its apparent significance or impact.

For example, there were dilemmas for parents in promoting the "self-determination" of their son or daughter. Many wanted to be involved in making decisions. They wanted the decisions that were made to contribute to their son's or daughter's personal development, security, and quality of life. At the same time they wanted to respect their son's or daughter's personal autonomy in making his or her own decisions. One mother reflected on this dilemma in the following way:

> *One of the things that I have a hard time with, as a parent, is my son's self-determination. I think of what institutionalization has done to my son over the years, and how that has altered or deprived the process of positive self-determination, and how so much of what a person determines in an institution is a negative thing in order to attract attention. And so when someone comes out of an institution, that has to be considered, when an individual is doing something. What is so difficult is to say, yes, that is his decision, he is determining that, so we have to let him do that. I have a hard time with that knowing some of the decisions my son is making right now. I could say, "why are you determining those things in your life, you can't do that". But no, you really do have to remember, as family, that you need perspective ... But at the same time, the balance has to be there. Ron has to be given the opportunity to learn that there are other ways, given that he learned to make certain choices when he was in the institution.*

Notwithstanding the need to strike the right balance, there were instances where individuals and families had experienced almost no control or input in decision making. In these instances, regaining a measure of control was perceived as the paramount concern. One such example of this was provided by the mother of a young man, Gerald, who had lived in many large and small "group homes" over the past fifteen years:

> *Gerald has been in so many different group homes, and so many times staff have ended up controlling and manipulating him, so much so that he has to leave. In one fourteen-bed facility he was in, the supervisor had manipulated Gerald so that my son told him everything, everything he did. The only way Gerald felt he could survive there was if he was always reporting on himself. From there he moved to a smaller residence — Gerald, who is fairly independent, and five severely handicapped individuals. There was no input. There was no planning. There was a good staff person who helped Gerald with a lot of skills. But the supervisor was on a power trip, all rules and orders. The staff eventually prepared a contract that said if Gerald swore or had a fight with a room-mate he would be kicked out. Gerald was getting desperate. I was getting desperate. So I went to the Association and said that either the supervisor goes or my son goes. They felt it was a "communication" problem. So they called in*

> *a social worker, the supervisor and myself. It was agreed that Gerald would go back with no programs, that any further programming would be developed with staff, the social worker, myself, and Gerald. And after the meeting was over the programming supervisor said, "I feel so powerless". But he wasn't powerless for long.*

By no measure did the accounts from the research paint the majority of front-line support staff as controlling, or manipulative. Staff faced their own dilemmas in making decisions, especially when no family were involved. How far were they to go in imposing programs in the attempt to realize positive change in an individual's life or to expand his or her range of choices? One residential support staff said:

> *Decision making is like a series of concentric circles. We often get stuck at the first level, the first circle. I ask Liz what she wants to do. She always says, "Go for coffee". This is what she always wants to do. That's O.K. But I also feel a responsibility to expand the "circle" of decisions she can make. I want to her to be able to find other things she likes to do, other places she likes to go. But that depends on me expanding the circle of what she can do. I have to create possibilities that she might choose at another time. But it can be very frustrating figuring out whose court the ball is in.*

Another dilemma for support staff was their own personal relationship and commitment to an individual. In relation to his experience with one young man, another residential support staff viewed the dilemmas in these ways:

> *We [support staff] decided to try to reduce Eric's "meds". We wanted to see if we could get rid of the drugs to see who the man is. We decided we would be willing to risk the adventure of shedding the drugs as a way of getting back to the essence of this man who had been disguised by medicine. I think it has a lot to do with expectations. We are interested in knowing Eric, the human being, not the drug label. But because we are the only ones in his life we have to set these expectations ... even though setting expectations is not part of my job, and maybe shouldn't be. So you find yourself being torn between being a support*

> *person, and being someone who is at the centre of another person's life ... As staff we also had to judge when we could legitimately take time away from the other men we are supporting, because we knew Eric would start demanding a lot more "one-on-one" when the drugs started to go. But how much longer could we let Eric wait before we helped him get rid of the drugs in his life?*

Parents and front-line support staff spoke very strongly in this research of the need to ensure that the "right" decisions are made when they need to be made, and that they are made in the "right way" — guided by principles of respect for individual autonomy, family involvement, maximization of opportunities for choice, and promotion of individual potential for development. When conflicts arose between these principles, staff and families wanted access to support to resolve them in order that the individual did not, unnecessarily, bear the cost of the conflict.

THE PROCEDURES FOR MAKING DECISIONS

The way in which these three kinds of decisions were made varied for the individuals and families who were interviewed. This variation depended to a large degree on the planning and funding mechanisms which were used to arrange, purchase, and manage community supports and services. As one set of mechanisms, service brokerage and individualized funding incorporated certain procedures for making these decisions. These procedures departed in significant ways from those established under more conventional and widely used planning and funding mechanisms.

This section provides a brief comparative description of the decision-making procedures used under planning and funding mechanisms, including service brokerage and individualized funding. Most individuals and families represented in this study have received supports and services under both sets of planning and funding mechanisms. *(See tables that summarize these mechanisms, types of decisions, and decision making procedures on pages 108 and 109.)*

MECHANISMS FOR DELIVERING PLANNING RESOURCES

The conventional planning mechanism: government or service provider-based planning

An individual, or his or her parents, usually comes into contact with the Ministry of Social Services and Housing (MSSH) — the "funding agency" — through a social worker based within a district or regional office of the ministry. If the individual is living in an institution, the social worker assigned to the institution is usually the point of contact for planning for community services. The planning role of the social worker can include some assessment of needs for support, a determination of funding and/or service levels required to meet individuals' needs, a determination of eligibility for financial resources and/or residential and vocational supports, and the identification of service providers to deliver the supports. Social workers may be assisted in these tasks by "financial assistance workers" and "resource developers" who also work for the ministry.

The support services purchased by the ministry are usually in the form of "programs" to be provided to individuals. Thus, it may be determined by the social worker that an individual "needs" twenty-four-hour residential care, a semi-independent living program, or a proprietary care service. The task of the social worker is to find a "match" or a "fit" between individuals, the available set of "program models" that the ministry is willing to fund, and service providers available to deliver the program.

Under tendering procedures for downsizing Woodlands, a social worker based at the institution meets with ward staff to "cluster" individuals in groups of three or four, and to prepare "non-identifying" profiles of needs for each individual. These profiles describe "level" of handicap, medical conditions, functional ability, and behaviourial characteristics.

The profiles for each of the clusters of individuals who are to move to the community are then made available to potential community-based residential and vocational service providers. Those who are interested in providing services prepare proposals based on the profiles of needs of each individual in the cluster, and submit a bid to the ministry.

When an individual already lives in the community, whether at home or elsewhere with paid supports, and it is determined that they require alternative arrangements, a social worker from a district or regional office will meet the individual and prepare a profile of needs. The profile may be used in referring the individual to potential providers. Providers will determine whether they can deliver appropriate supports within the funding commitment the ministry has made. Agreements will then be negotiated with the service provider.

In ongoing service delivery, the planning resources available to the individual are usually delivered through the service provider. Front-line support staff and other professionals usually provide some form of individual program planning within terms set by the service provider, or required by the funding agency. Service providers may make counsellors available to assist individuals in coordinating their service needs among various service providers.

As part of their case-management function, social workers carry out periodic reviews of the services an individual receives. As well, the ministry has instituted a process to review the community services received by individuals who moved from Woodlands under the tendering procedures. At the time of the study, province-wide standards for delivery of community residential support were under consideration by a Provincial Advisory Committee on Services to the Handicapped. The design of a monitoring function to ensure compliance with standards was under review as well.

The autonomous fixed point of response and service brokerage

Service brokerage is based on the principle that individuals and their close families and friends should be able to make decisions about the supports and services they require. Service brokers are to be fully accountable to individuals and those family or friends that the individual designates to assist in decision making. The CLS believes that this kind of accountability can be ensured by the broker's autonomy from the funding agency and service system, and by their accountability to a fixed point of response.

The service broker may assist in a number of functions that facilitate the decision-making process for individuals and their families including: identification of individuals' goals, strengths, and needs; provision of information about the kinds of supports that could meet these needs; identification of potential service providers; assistance in negotiations and contracting with the funding agency and service providers; and consultancy on the implementation of service agreements.

Based on the identification of goals, needs, and strengths, and decisions about the kinds of supports to be used, service brokers prepare a General Service Plan (GSP). The GSP includes a statement of strengths, needs and goals of an individual, an identification of required residential and other supports, and a costing of these supports.

A recent monograph on service brokerage states that general service planning should result in a plan that:

> *"[articulates] a vision of community living that the individual hopes to experience ... contains the organized information about an individual's strengths, needs, and*

> *personal vision for community living ... a statement of how the vision for community living can be achieved ... such things as where a person lives, where they work, learn or play, as well as how they communicate and take care of their personal and medical needs".*[7]

The CLS evolved general service planning when the organization was first faced with finding ways of moving individuals from the institution to the community under Project LIFE. The experience with one of the first individuals the Board agreed to support was an opportunity not only to negotiate with the Regional Office of the Ministry for individualized dollars, but also an opportunity to develop a plan on which individual costs would be based. For the broker involved, the experience with this individual was crucial to how the CLS came to think about and practise planning:

> *We had to grapple with what a planning process would be, what did it mean, what kind of a tool would we use, would it be an existing one, would we have to come up with something new? ... There was one young lady who was seen as a crisis situation by the [CLS] Board, because her mother had pulled her out of the institution one day [late in 1977]. She had found her starving, essentially. She had been given some drugs and wasn't eating anymore, and so she brought her home. The Region [Regional Office of the Ministry of Human Resources] was having some difficulty with what to do to support this young lady and her family, and so the Board agreed to support them. Around her we came up with a general service plan format that was attempting to talk about who the person was, a kind of profile, and then a plan of action ... This plan was taken to the Regional Manager and walked through, this profile of the person. It wasn't a program that was being asked for. We talked of outcomes, the "dream" for this young lady, and then some discussion of what that would cost.*

This emphasis on the individual, his or her "dream", who the person is, has been a continual thread in the development of the GSP process. This is evident in the service brokers' more recent perceptions of their own work. As one broker stated:

> *Last year [1987] we tried to move further away from*

> *descriptions and labels. We see the GSP as a document that shapes the perceptions of people who work for the individual. So we're moving towards using the GSP as part of an educational strategy. And we're much more up front about labelling as an institutionalizing process.*
>
> *We don't accentuate the GSP as a form or format. Its first function is the process of planning. It is a tool that becomes the road map for developing service, it should then become the contract.*

The CLS believes that planning should culminate in a contract that provides real status and accountability to the individual. The logic underlying the emphasis on the contract is a recognition by the CLS that both the service provider and the funding agency gain their status in the service system through the contractual agreements they strike. If an individual is to gain some status, the CLS believes he or she also needs to be party to the agreements that are made about them.

Autonomous service brokerage and individualized funding have been fully implemented only for a small number of individuals served by the CLS. For these individuals the Ministry of Health has agreed to allocate funding on an individual basis, and to contract with the CLS to provide up to 200 hours of service brokerage per individual. The functions of the service broker as specified in these contracts include:

- acquisition of knowledge and information by getting to know the individual, and carrying out research related to their needs;

- exploration of resource options in the community which includes the identification of potential specialized service providers, and the identification of generic medical and professional supports;

- general service planning;

- negotiation of funding agreements with the ministry, and service agreements with the service agency, based on the general service plan;

- transition planning, which includes interpretation of the individual's needs to service providers, preparation for the move of the individual to his or her residence, consultation on staff training, etc.

Service brokers are to be available after individuals begin receiving services. At the request of the individual, or his or her family, brokers are to provide assistance in ongoing mediation and negotiation with the service provider. Where individualized funding is in place, service brokers have also been contracted to provide staff training, and to monitor the implementation of the contract for service delivery.

The CLS stresses the value of advocates and personal relationships outside of paid support staff. Family and friends are to have uninhibited access to the service, regulated only by the individual. For those individuals who do not have family or friends involved in their lives, support staff are encouraged to facilitate development of personal relationships. The CLS has encouraged families to play a role in activating the decision-making process for ongoing service delivery, in individual planning, and in providing informal monitoring. Families may seek assistance from brokers in carrying out these roles.

MECHANISMS FOR DELIVERING FINANCIAL RESOURCES

In Canada, financial resources are allocated by governments for income assistance and for the purchase of supports and services. Financial resources are generally allocated under the federal-provincial funding arrangements of the Canada Assistance Plan, the federal-provincial Established Programs Financing arrangements, federal-provincial agreements under the Vocational Rehabilitation of Disabled Persons Act, and other provincial funding sources. In British Columbia, the authority for allocating financial resources for income assistance and social services is granted under the provisions of the Guaranteed Available Income for Need Act (GAIN).

Income assistance is provided to individuals in British Columbia to meet their basic living expenses. It is an entitlement for those who meet a financial needs test. This entitlement is legislated under GAIN and is administered by the MSSH. This ministry has been the primary authority within the provincial government for funding and programs for people with a mental handicap.

There are two entitlements for individuals with a mental handicap provided under this legislation. Basic Income Assistance is provided to all individuals aged nineteen and over who meet a financial needs test. Assistance includes a shelter and utilities component, and a support allowance. Supplementary benefits, through "GAIN for Handicapped" are provided to individuals who meet the criteria of "handicapped person". This supplementary entitlement is meant to respond to financial needs that arise because of an individual's permanent inability to gain financial independence through employment.

Where individuals require residential, vocational, or other support because of a disabling condition, they may be eligible for additional funding under Section 2 of the GAIN Act. However, while individuals may be eligible for additional funding because of their demonstrated needs, they are not entitled to this funding.

Financial resources for supports and services are conventionally delivered under the funding mechanism of "service funding". "Individualized funding" is described below as an alternative to service funding. "Individualized costing" is described as partially implemented individualized funding, which has been in place for the majority of individuals served by the CLS.

Service funding

In the case of service funding, the service providers who are chosen to deliver residential and vocational supports receive funding from the MSSH, and/or the Ministry of Health through purchase of service agreements. The contractual arrangement under service funding is between the provincial government and service providers. It is incumbent on these two parties to reach a decision on the supports required by any particular individual. The service provider may or may not be willing to deliver services at the rates proposed by the funder. Given that the provider does decide to deliver services to an individual(s), it is on the basis of their needs as a service provider (overhead, staffing, operating costs) that funding is negotiated and allocated.

Where tendering procedures are used, service providers submit proposals to the MSSH to provide service to an individual(s). The ministry's acceptance in principle of a bid by a service provider serves as a funding commitment to that provider. The funding agency and the service provider then negotiate a final proposal and budget for delivery of services.

Through the tendering procedures, more than one service provider may submit a proposal to deliver services to the same cluster of individuals. In these cases the MSSH, in conjunction with senior officials at Woodlands, determines which service providers are best able to meet individuals' needs and meet the accountability requirements of the ministry. Once this decision is made, negotiations with a service provider begin.

The ministry may also provide funding commitments through referral. When an individual has been determined by the ministry to be eligible for funding, they may refer an individual to a service provider. If the service provider is willing to provide services, they accept the funding commitment from the ministry, and develop a proposal and budget for service delivery.

In most cases, the MSSH uses a service funding approach to deliver individuals' income assistance, as well as the funding for residential and vocational supports for which their eligibility has been determined. That is, the income assistance to which individuals are entitled is automatically allocated to the service provider contracted by the ministry. That portion of income assistance which is paid to the service provider is considered to be the individual's "user fee" for use of the services.

Financial resources for ongoing service delivery are usually allocated through the purchase of service agreements between the funding agency and the service provider. Procedures for financial accountability are instituted as part of these agreements. As a condition of funding, the ministry may require that some procedure for individual planning be implemented. This requirement is intended, in part, to ensure accountability to individuals' decisions. It also serves as a way of managing the primary line of accountability in ongoing service delivery — that of the service provider to the funding agency.

Individualized funding

Individualized funding is an approach to allocating financial resources that begins with the individual. Allocations are not made to service providers to deliver "programs", but to individuals. Individuals and their families and other personal supports, with assistance as required, negotiate with the funder to determine the supports and service providers to be used. The underlying principle of individualized funding is that individuals and their families should have status to determine which goods and services will be purchased to meet their needs.

Procedures for managing and negotiating funding allocations revolve around the General Service Plan (GSP). Under individualized funding, the funding agency makes funding commitments to individuals prior to any purchase of services. The individual, with close family or friends that they may designate, then begin the general service planning process with the assistance of a broker.

The preparation of a costed GSP to be used in funding and contract negotiations involves assessment of physical, social, and psychological needs; translation of these needs into specific goods and services; and costing of these goods and services. (For a detailed discussion of costing the GSP see Appendix C.) The costed GSP becomes the basis for negotiating contractual arrangements between: 1) the individual and the funding agency; 2) the individual and the service provider; and 3) the funding agency and the service provider, where it is the funding agency that purchases services.

The General Service Plan is to be costed and funded as a responsible plan. The CLS believes that negotiations based on the GSP can result in levels of funding that are both fiscally responsible and adequate to purchase quality services and supports.

The CLS believes that tracking of financial expenditures, made by a provider on behalf of individuals, should be an available service. Access to individualized tracking of expenditures and accounting information is meant to provide individuals, their families, and, where requested, their broker, with a mechanism to review whether the conditions of the funded general service plan are being met. The CLS has implemented some tracking procedures for the services it provides. It is also developing the technology to provide such a service on-line.

Individualized costing

The relationship between the GSP and contractual status largely remains an ideal for the CLS. For the majority of individuals served by the CLS, services are funded through the service funding mechanism used by the MSSH. The CLS has partially implemented individualized funding in these instances through "individualized costing". Under these arrangements, the ministry has made funding commitments to the CLS to deliver services. Individuals and families then have access to a service broker attached to the CLS. The brokers assist in preparing general service plans which are used to "individually cost" services. These plans are also used as the basis of final negotiations with the ministry.

Under individualized costing the dollars are still allocated to the service provider (the CLS) within the framework of "service funding". Thus, the service-funded contracts signed with the CLS are for the provision of residential services to groups of individuals who live together.

Individualized costing differs significantly from an individualized funding approach. Although the B.C. Ministry of Health does not claim to have introduced individualized funding, and does not deliver financial resources directly to individuals to purchase services, it has recognized the principle of allocating funding according to individual need, and on the basis of a GSP which has been prepared and costed with the assistance of a service broker. The ministry has provided the opportunity to some individuals and their families to determine the contractual conditions on which service providers will be contracted. In these cases, service providers receive funding on the basis that they will meet these conditions.

For the purposes of this study, those instances in which individuals and families have been given contractual status in funding and contracting arrangements have been identified as cases of "fully implemented" individualized funding. Arrangements for individualized costing under a service funding approach have been identified as "partially implemented" individualized funding.

CRITERIA FOR DECISION-MAKING OPPORTUNITY

Decision-making opportunity is used in this study as the measure of the goal of self-determination, autonomy and dignity. In order to assess the impacts of service brokerage and individualized funding on achieving this goal, a set of criteria of decision-making opportunity has been identified. These criteria were identified through the interviews for the study. On the basis of individuals' and families' experiences in accessing and using community supports, five criteria of decision-making opportunity were identified:

- access to planning resources
- access to financial resources according to individual need
- accountability to the individual for decisions made
- availability of a range of community-based alternatives
- recognition and status for close family and friends

ACCESS TO PLANNING RESOURCES

Individuals and their families stressed throughout the research that in order to be able to make decisions about supports and services they needed planning resources. They wanted information about community services, and assistance in defining needs, in securing financial commitments from government, in negotiating with service providers, and in dealing with ongoing service delivery issues.

The question for the research was whether service brokerage provided access to these resources and, if so, whether it was able to provide equitable access to all individuals served.

ACCESS TO FINANCIAL RESOURCES ACCORDING TO INDIVIDUAL NEED

Those who were interviewed indicated that another important criterion of decision-making opportunity was that individuals be able to access funding for goods and services on the basis of their particular needs. They also wanted the definition of an individual's needs to be related to an understanding of his or her personal goals for living in the community, and to the expectations and hopes of his or her family. Many who were interviewed felt that decision-making opportunity was compromised when access to funding was not based on individual need, but rather on program or service criteria which individuals had to meet if they were to receive services.

The question for the research was whether individualized funding, in its limited implementation, has provided a delivery mechanism that allocated financial resources on the basis of individual need.

ACCOUNTABILITY TO THE INDIVIDUAL FOR DECISIONS MADE

Many of those who were interviewed felt that decision-making opportunity was most fully realized when decisions that were made about models of support, service providers to be used, and ongoing service delivery were accountable to the individual. Those who were interviewed also felt that decisions should be accountable to family or friends who were designated by the individual to speak on his or her behalf.

Accountability issues have usually been framed in terms of accountability of a service provider to a funding agency. The experience of individuals and families in this study indicated that providers and the funding agency have not always been able to ensure accountability to the individual.

The question for the research was whether the mechanisms of service brokerage and individualized funding enabled greater accountability to the individual for decisions made.

AVAILABILITY OF A RANGE OF COMMUNITY-BASED ALTERNATIVES

Another important criterion for decision-making opportunity was identified as the availability of a range of community-based alternatives from which people could make selections. Individuals and families felt that alternatives were necessary in all areas of decision making: the models of community support that would be used; the service providers who would deliver the supports; and the ways in which decision making would be managed in ongoing service delivery. The importance of a range of alternatives was underscored by the experience of many parents who were interviewed. The lack of alternatives was one factor which led to the the institutionalization of their sons and daughters from 1950 to 1980.

The research asked about the extent to which service brokerage and individualized funding increased the range of alternatives from which decisions could be made about supports and service delivery.

RECOGNITION AND STATUS FOR CLOSE FAMILY AND FRIENDS

Another criterion of decision-making opportunity was that recognition and status be secured for close family and friends in the decision-making process. Parents interviewed in this study believed that important functions of close family and friends were: to keep the individual at the centre of all decisions made; to support the individual to make decisions; and, where need be, to make decisions on his or her behalf. There were various ways in which families and friends worked to keep the person at the centre. These included: advocacy; communicating a personal history and a sense of the person; keeping records of commitments by government officials; and providing personal information not available to professionals who were involved in decision making.

However, recognition and status were not meant to suggest that a high level of family involvement necessarily ensures self-determination, autonomy, and dignity for individuals. As in any individual's life, "actively involved" families can also restrict autonomy, and in the very worst cases, inflict forms of abuse.

Parents who were interviewed felt that decisions about their involvement should always be made between individuals and their families, or other close friends. They felt that negotiations with a service provider or funding agency about how family involvement was to be managed might be required. However, from the parents' perspective, the funding agency or the service provider should not be in a position to restrict the access by families or friends to the decision-making process or the service setting for any reason. Rather, they should actively promote involvement of family and friends. The exceptions are in cases where access by family or friends clearly and demonstrably contravenes the wishes or basic rights of the individual.

The question for the research was whether service brokerage and individualized funding provided for the recognition and status of family and friends in decision making, in ways that promoted the self-determination, autonomy, and dignity of individuals.

The following five chapters discuss findings from the evaluation of service brokerage and individualized funding, in relation to these criteria of decision-making opportunity.

Notes

[1] Community Living Society, "Beliefs and Values and Principles as Developed by Parents," In *Exploration* (Vancouver: April 29, 1985), p. 3.

[2] Community Living Society, *Community Living Society: The System* (Vancouver: no date).

[3] Eric B. Emerson, "Evaluating the Impact of Deinstitutionalization on the Lives of Mentally Retarded People", *American Journal of Mental Deficiency*, vol. 90, no. 3 (1985): 277-288.

[4] Peter Mitler, "Quality of life and services for people with disabilities," *Bulletin of The British Psychological Society*, 37 (1984), p. 220.

[5] S. Bercovici, *Barriers to Normalization: The Restrictive Management of Retarded Persons* (Baltimore: University Park Press, 1983) p. 42.

[6] Gloria Kishi, et. al., "Daily Decision-Making in Community Residences: A Social Comparison of Adults With and Without Mental Retardation," *American Journal on Mental Retardation* vol. 92, no. 5 (1988): 430-435.

[7] Brian Salisbury, et al., *Service Brokerage: Individual Empowerment and Social Service Accountability* (Toronto: The G. Allan Roeher Institute, 1987), pp. 25-26.

CHAPTER 2

ACCESS TO PLANNING RESOURCES

Many individuals and parents who were interviewed indicated that in order to make decisions about community services they required information, planning assistance, and negotiating assistance.

Information was required about the following: funding sources and how to secure financial commitments for individuals; assessments of an individual's needs; options for community support; and potential service providers. In addition, some parents found that a critical information need was the capacity to store and manage information concerning assessments, financial commitments, and community resources. This information management was considered crucial in negotiating for funding and services. They believed they could negotiate more effectively when they had kept track of commitments made by government officials, options that were available, and commitments by service providers.

Another important information resource they identified was political knowledge. This consisted of information about: how the funding agencies work; the points of intervention in the political process that can be used to secure commitments; and effective ways to negotiate and advocate on behalf of an individual.

Many wanted planning assistance in order to help define an individual's needs, his or her personal goals, the needs and wishes of the family, and the strategies for meeting needs in the community. They also wanted access to assistance in resolving issues and conflicts that arose in ongoing service delivery.

The activities of planning and decision making were described by many as an ongoing process of negotiation. They described the process of negotiating with doctors, therapists, social workers, and service providers. While negotiation absorbed extensive time and energy, many found that the ability to negociate was critical in: deciding how behavioural and other assessments would be used; identifing appropriate community supports; arranging funding; finding service providers; and working out how daily activities would be managed.

FINDINGS

For many of those who were interviewed, service brokers were in a position to provide information and assistance in planning and negotiating. They felt that brokers had often been more effective in providing needed assistance than social workers employed by the MSSH. However, the study found that there is a need for planning assistance in ongoing service delivery. The study also found wide variation in access to the assistance of the service broker. Findings about the impacts of service brokerage on the provision of planning assistance include:

- planning centred on the individual
- autonomous planning and negotiating assistance
- assistance in conflict mediation
- need for ongoing planning assistance
- wide variation in access to service brokerage

PLANNING CENTRED ON THE INDIVIDUAL

Service brokers were found to be in a unique position to begin the planning process with individuals' hopes, personal goals, their strengths, and their needs. One mother identified the impact of the service broker in this way:

> *The broker got involved. He met with Sean at the institution, he talked with him to find out what he wanted, his vision and goals. He said he would try to put into words what Sean wanted. We drew on the broker's expertise, his information resources, his way of writing and putting things into words.*

Similarly, another mother said:

> *The broker and the CLS didn't want control. I didn't have to fight with the broker to get what I wanted. Christine was treated as an individual for the first time by a professional ... The broker went immediately to Christine — watching, talking, playing. He got to know the family, what was important to us, our values, expectations, morals, and standards. He got to know what Christine wanted. He talked to social workers, friends, and staff at the Hospital. He developed a sense of Christine from input by all of these people.*

Many individuals and families indicated that service brokers had been able to get all the facts, and provide the total picture when it came to securing funding and information about community supports and services. They also felt that social workers had not been able to provide needed information about funding or support alternatives. One mother, whose son had lived in many group homes in the community, believed that social workers should not be involved in planning. She said:

> *Social workers shouldn't be involved in planning for individuals. They have large and generalized caseloads and aren't able to develop the expertise they need. The ... social worker didn't know about resources in the community and so was not able to help me at all in finding a place for my son in the community.*[1]

Another mother voiced a common experience of those who were interviewed. Before her son had been placed in institutional care she had sought information from the funding agency, local associations, and other service providers about community alternatives to institutional care. Because she could find no such information, the decision to place her son in Woodlands School became inevitable.

> *What I wanted was to know how to put it all together so that my son could meet his needs living in the community, and I couldn't find that information anywhere ... When we were able to bring my son out of the institution it was the broker who was able to help me put it all together.*

This mother attributed her eventual success in arranging funding and community supports to the broker's ability to access information that was tailored to her son's requirements, and to assist in negotiations around those requirements.

AUTONOMOUS PLANNING AND NEGOTIATING ASSISTANCE

The autonomy of brokers from the funding body was identified by families as an important feature of service brokerage. They felt that this autonomy increased the accountability of the broker to individuals. One mother saw the autonomy of the broker in this way:

> *The broker wanted to find out what Mark's dream was. Mark said that he wanted an apartment of his own and to be able to work in a supermarket. The broker said that he would find some alternatives ... The fact that the broker is an impartial person, working on behalf of Mark and not tied to anyone except his Board, gives him a flexibility. He's not trying to look good in the eyes of the Ministry. I see the broker as not having to work in that structure.*

Another parent found that the broker was able, because of his autonomy, to assist in dealing with what she perceived to be the "inequities" in the system:

> *The broker was so important to us in developing a resource for Maureen ... I'm a social worker, I've worked for social services for a number of years. Social workers won't tell you what might be available in other regions. The broker knows the services and the disparities, so he can play regions off against each other. He can tell social workers he knows what's available in other regions.*

One example which demonstrates the broker's unique role in negotiations involved an individual and his family who were seeking a new proprietary care agreement because they had been unable to secure adequate support under previous levels of funding. The young man had been through many proprietary care situations and group homes, unable to find one that suited his needs. The family was able to arrange for a broker to assist in the negotiations with the ministry even though CLS services were not involved. An increase in funding was negotiated from Level I to Level III (categories of funding established by the MSSH), and the young man and family were able, for the first time, to choose the provider. The broker was involved to assist the provider in developing an arrangement that most suited the needs of the young man.

In the estimation of the parents, it was not that their son's needs had changed that resulted in this increase of funding. What had changed was the assistance of a broker and the willingness of a new social worker to renegotiate funding. From his perspective, the broker felt that he had assisted the young man in being treated more equitably. The parents felt that it was only because the broker was autonomous from the funding agency that he was able to play a role in assisting them and their son in the negotiations with the ministry. The mother commented:

> *The broker was important because he was impartial. If you work for the MSSH you have a conflict of interest. Brokers should be doing the planning, not social workers. If things had been properly planned in the first place everything would not have been set up to fail. Mark would not have been through this hell.*

Many individuals and families who were interviewed believed that if social workers were attached to the funding body they were not in a position to play a strong negotiating role on the individual's or family's behalf. Some believed that ministry social workers were placed in an untenable conflict-of-interest situation in decisions about community supports and services. They believed that the social worker was compelled, as an employee of the government, to negotiate within the terms and conditions which the government laid down. One mother said:

> *The broker is not completely autonomous. He works for my son. So he is autonomous from services and the government but acts for my son. If I run into a problem [the broker] will suggest I take this or that route. I do the actual advocating for Sean ... The way I see a social worker is that they are adversaries. The broker is the opposite. He's not in an adversarial role.*

The director of one service agency, herself a social worker for the MSSH in the past, perceived the conflict of interest for the social worker in this way:

> *It astounds me that we're training social workers to go into the system to serve the system. It's part of their mandate as a social worker to serve the system, to be the*

> *person responsible for accountability to the system. It's a contradiction. How can they be accountable to the individual? They get into the system and is it any wonder that they're schizophrenic?*

Lack of autonomy of the social worker from the funding agency was seen by individuals and families to have a number of consequences.

First, the perceptions of social workers had a determining influence on the kinds of support services or program models that were determined to be within the realm of choice. Yet the social worker often held onto perceptions about long-term goals or interests that were incompatible with those of the individual and the family.

Second, decisions about support services were determined by the social worker's understanding of the community and community resources — an understanding which some individuals and families felt was inadequate.

Third, limited contact with an individual could give a prominence to "behaviours" in the perception of the social worker that varied from that of others who spent more time with the individual. This perception could determine the kinds of support the social worker was willing to recommend for funding.

Fourth, social workers' understanding of individual needs seemed to be shaped by the set of program responses made available through policy and legislation. However, if an individual could not be fit into a program because of his or her unique needs, social workers did not always feel that they had a mandate to continue to plan and search for options. When this happened, the outcome was often one of crisis for the individual and the family.

ASSISTANCE IN CONFLICT MEDIATION

Parents and support staff who were interviewed found that once service delivery began, the network for managing communication between families, individuals, and various service providers was sometimes inadequate. They had found that this could result in conflict and misunderstanding. Parents identified two key factors that could lead to conflict.

First, some parents who were interviewed stressed their powerlessness to advocate for their sons or daughters in the face of the power of the service provider. Although some parents who were interviewed were very adept at playing an advocacy role, others found themselves feeling intimidated by service providers, unaware of the demands they could make on a provider, and unable to discuss their concerns. Even those parents with the greatest facility in managing communication and decision making with service providers found that when they strongly advocated for their son or daughter, communication with the provider could break down.

Second, those who were interviewed found that assumptions about an individual's needs and goals could vary among the individual, parents, and different service providers. As a result there were sometimes conflicting views about what constituted appropriate responses by service providers. In addition, it was sometimes difficult to agree on how to manage communication, or resolve differences. At these times they felt they needed another, more objective, player who could mediate the conflict and differences.

Brokers' assistance in conflict mediation was noted by both families and support staff. One mother, whose daughter receives residential supports from a non-CLS provider and attends the CLS vocational service, found the broker's support extremely important in mediating differences and negotiating service delivery with the service provider:

> *When I started to foresee problems I called him. I had never had a broker before. It's supportive to know he's out there working for my daughter. Right now she does not seem to be too unhappy. But sometimes she comes to the day mod crying ... They [the residential provider] want to make the decisions and to have control over her. I'm compiling a lot of things to talk to them about. But I want my broker there when I meet them.*

A support worker in the CLS vocational service also found the broker useful in playing this role:

> *I will call a broker — who has information and expertise about resources — to help resolve differences between staff, or when I hit a brick wall. House staff may say, "I don't want an individual doing this, they're not independent enough", which could be a different position than mine. The broker will act as a mediator between staff to resolve the issue. They act as a chairperson. They set up a meeting between all the staff, and ask what's happening in this person's life. They're able to take information from both sides and help to formulate a direction for the individual. The broker helps us to realize that the individual is the focus.*

THE NEED FOR ONGOING PLANNING ASSISTANCE

Interviews with some parents and support staff suggested that service brokers had not been effective in all cases in helping them identify the appropriate planning process for particular individuals. While the GSP was considered to be a useful document in guiding the transition of an individual to the community, some support staff felt that it was not as useful in ongoing service delivery. Further, many support staff felt that service brokers and the CLS had de-emphasized formal planning procedures. They perceived that this was a response to a legitimate concern that formalized individual planning could lead to institutionalizing and over-regulation of individuals in the community. However, some support staff felt that this de-emphasis resulted in a kind of vacuum in designing even informal plans which could respond to individuals' changing needs and personal goals. Some felt that this planning vacuum placed certain individuals at unnecessary risk of not receiving the support they needed or wanted.

Other support staff felt that the de-emphasis on a formal approach gave them the opportunity to be more responsive to individuals because they were not constrained to deliver "programs". Some felt that the de-emphasis on formal planning encouraged flexibility and adaptability on the part of support staff. One residential support worker, reflecting on how she managed planning without a formal IPP process, said:

> *When Jeremy finished school we sat with him and his mom and talked about possibilities. Together we decided that vocational training was the next step and the day mod was a good place to start. But it seemed the more important decision was when and how we would do this and support Jeremy. Should he begin immediately? Should he take the summer off? Because Jeremy is not verbal, we decided we would let him try two options — spend a few days at the day mod and spend some time at home. After he tried both we could sense he wanted some time at home, to take the summer off. So the staff figured out the ways we would manage the summer with Jeremy at home.*

There was no consensus among those who were interviewed about how individual planning should be managed in ongoing service delivery. Many felt that regardless of the approach to planning used for any particular individual, brokers had a more active role to play in initiating individual planning in ongoing service delivery. This was a concern especially for those individuals who had no family or friends to advocate for them. For those who did, it was felt that brokers had a greater role to play in identifying ways in which ongoing individual planning could be carried out.

WIDE VARIATIONS IN ACCESS TO SERVICE BROKERAGE

While service brokers were found to be in a position to provide the planning resources that increased the opportunity for individuals and families to make decisions, the research found a wide variation in access to service brokers. This variation was found to be the result of five factors: (1) limited funding for service brokerage; (2) barriers in the administration of service funding; (3) limited availability of individualized funding; (4) lack of close family and friends who were able to advocate for an individual; and (5) inadequate procedures for activating service brokerage in ongoing service delivery.

Limited funding for service brokerage

Annual funding under the CLS/MSSH agreement for service brokerage has not been increased since its implementation in 1978. While the grant provided funding to employ up to twelve brokers in the late 1970s, the grant is now only sufficient to employ three brokers. According to the CLS, the organization received no administration funding under the residential service contracts with the MSSH from 1980 to 1985. Consequently, the agency had to use a large portion of the annual grant for service brokerage to cover administrative costs of the agency.

While the resources for service brokerage diminished, the number of individuals brokered for by the CLS increased substantially between 1980 and 1990. This resulted in a corresponding restriction in the time that brokers had available for any one individual, except where contracted by the Ministry of Health for a particular individual. Brokers have tended, therefore, to allocate their time in a reactive manner — where there were crises — and according to the demands voiced by particular individuals and families.

Barriers in administration of service funding

The way in which service funding has been administered has had a significant impact on the general service planning process. Because service funding entails transactions and agreements only between the government and the service provider, there is no administrative requirement or incentive to provide status for individuals and families in negotiations about the kinds of support services or service providers they use.

Prior to the implementation of tendering procedures for downsizing Woodlands, the CLS was able to address this disincentive to involving individuals and families in decisions about community supports. The CLS insisted, and the MSSH agreed, that negotiations be carried out only on the basis of individually costed GSPs developed with individuals and families. Up to 1986, service brokers, within the confines of their own resources, allocated extensive time to the development of the GSP before entering final budget negotiations.

The administration of service funding through the tendering procedures eliminated this possibility. Decisions about supports to be used had to be determined on the basis of the non-identifying profiles of need provided by the MSSH, without brokers being able to meet individuals or families. For those moving from Woodlands after 1986, therefore, service brokers were only able to play a minimal role in assisting them and their families in choosing the kinds of support that would be delivered.

Limited availability of individualized funding

The use of different mechanisms for delivering financial resources has had an effect on equitable access to the planning support of a service broker. Those individuals who happened to be moving to the community from an institution with funding commitments from the MSSH and under tendering procedures generally received little or no direct planning resources through service brokerage. Those few individuals who moved from institutional care under individualized funding were assured access to the services of a broker who was contracted to provide between 160 and 200 hours of planning support.

Lack of close family and friends able to advocate for an individual

The ability of close family and friends to advocate for individuals contributed to the variation in the planning assistance they received from brokers. Those who had strong advocates tended to have easier access to a broker in ongoing service delivery than individuals without strong advocates.

In one instance, a young woman who moved from Woodlands under the tendering procedures had vocational services purchased on her behalf from the CLS and residential supports purchased from another provider. This was the only instance, among those individuals included in the study, in which a GSP was not prepared. This was due to the fact that the residential agency took most of the responsibility for managing the transition from Woodlands to the community. Because there was no contracted planning role for a service broker there was little relationship between the broker and the residential provider.

Eventually a broker did become involved because the woman's mother was very effective in using the broker. She had not been aware that her daughter had a broker until she was informed by a support staff at the vocational day program. This was one example which demonstrated the importance, for the effectiveness of service brokerage, of family or friends who could advocate for an individual. The lack of families or friends who could play this role appeared many times in the research as a barrier to accessing the planning resources of the broker.

Inadequate procedures for activating service brokerage in ongoing service delivery

Historically, general service planning and the arrangement of support services has absorbed a large proportion of service brokers' time. However, the demand for their assistance in ongoing service delivery has steadily increased as the numbers of individuals receiving residential and vocational services from the CLS has grown. Service brokers were often requested by individuals, families, and support staff to assist in making decisions in ongoing service delivery. Their assistance was requested in regard to: resolving conflicts with and between support staff; negotiating with service providers over individual programs and therapies; renegotiating funding; accessing generic education, recreation, and health care services; individual planning; purchase of needed devices; and staff training.

The CLS has stated that, ideally, a broker provides assistance in ongoing service delivery as needed and when requested by the individuals and families to whom they are accountable. This process was found to be effective in a number of the cases studied. However, this ideal was not always realized because of a lack of funding for brokerage, an inability of many individuals to make contact themselves, and the lack of family and friends who were able to advocate for individuals. Residential support staff reported that brokers had not been involved in or were not sufficiently aware of some situations which staff felt had clearly suggested the need for their intervention. One mother, whose daughter had received services from the CLS, felt that when her daughter needed the intervention of a broker it had not been available:

> *When we had a situation of high turmoil in Maria's life, there was no capacity to respond to the trouble spots. The capacity didn't seem to be there in the brokers. We haven't put into place the support systems that can respond.*

Some support staff felt that brokers should be available to act as advocates for the individual when he or she had no family or friends able to play this role. Some staff found that brokers, in particular cases, had played very strong advocacy roles. As well, they felt that brokers were not as available in ongoing service delivery as they had been when individuals were first getting settled into a new service situation. As one residential worker said:

> *The planning initiative is on my plate. I don't feel the impetus from the broker. If the brokers are there to be an advocate, they should be there. From what I've heard, the broker plays a great role in getting people into the community. But then, we don't hear from them when we think we should.*

The administrator of one non-CLS service agency also indicated that if brokers had the time they could be more fully involved in the ongoing individual planning process. The administrator felt this would remove the function from the service provider and would provide a "quality check" on the service provided. She said:

> *We [as service providers] feel totally responsible for planning and pulling people together. Brokerage would ensure a check on the service I was providing — a quality check. I see the role of the broker as connecting everyone in the system. For brokerage to be effective, brokers must spend a lot of time with families and service providers.*

The brokers' interpretation of their role differed in some important respects from the perspective of some support staff, families, and non-CLS service providers who were interviewed. Brokers felt they should not be held accountable for delivering ongoing individual planning, crisis response, monitoring, or advocacy within the service system. They saw individual planning and crisis response as the responsibility of service providers who were contracted in part to provide these supports. They felt, however, that the GSP should set the parameters of ongoing individual planning. They believed that advocacy was the responsibility of the close family and friends of individuals. And they believed that monitoring was either the responsibility of government, families, volunteer agents, or some combination thereof.

Brokers stated that linkages among these various components in ongoing service delivery should generally be self-sustaining. If individuals or families want to reconsider support options or service providers, brokers can be contacted. They felt that brokers should be available to facilitate the development of linkages, and to deal with the conflicts between the various actors in the system.

Brokers do, however, acknowledge that they have some responsibility for monitoring the implementation of the General Service Plan and service contracts, given that they are an individual's agent. Where crisis situations have erupted, they have resulted in part from inadequate monitoring of GSP implementation. To increase their capacity to carry out this function, two initiatives were recently put in place. First, through a staff training program for CLS residential and vocational support staff, brokers clarified their own role, the role of support staff, and the role of family and friends in planning, advocacy, and monitoring. Second, they have begun a systematic "review" process in which they visit individuals for whom they broker at periodic intervals. This study was not able to evaluate the impact of these initiatives because of their recent implementation.

SUMMARY

Service brokers were perceived to increase the decision-making opportunity of individuals and families. This was due to a number of factors which include: their autonomy from the funding body; their ability to begin the planning process with the personal goals of individuals and families; the access they provided to needed information; and their assistance in carrying out negotiations with the funding agency and service providers. Many who were interviewed compared the role of the broker to the ministry social worker. They felt that the social worker was unable, because of his or her attachment to the funding agency, to provide effective assistance to individuals and families in negotiating funding and service arrangements.

In response to a concern that the formal IPP process did not ensure accountability to individuals, and that it had the potential to undermine accountability, the CLS has tended to de-emphasize formal individual planning procedures for ongoing service delivery.

However, this has sometimes left CLS support staff, individuals, and families without any form of planning process to manage decision making in ongoing service delivery.

There was a wide variation in access to the services of the broker. This was a result of factors internal to the CLS and to external factors. Until recently the lack of any systematic procedures by service brokers for monitoring the implementation of the GSP tended to exacerbate the variation and inequity in access to brokers. External factors have also contributed to a reactive approach to allocating the time and expertise of brokers. These external factors include: limited funding for brokerage; the administration of service funding which restricts status for individuals in decision making; the tendering procedures for downsizing Woodlands; the unavailability of individualized funding; and the varying strengths and participation of individuals' advocates.

The issue of limited access to brokers in ongoing service delivery and the lack of mechanisms for activating their involvement when an individual was without advocates to play this role, was perceived by support staff and families to be an issue of considerable concern. Brokers felt they were not to be held accountable for ensuring adequate advocacy, individual planning, monitoring, and crisis response — functions which others sometimes attributed to them.

The effectiveness of service brokers in mediating conflicts in ongoing service delivery was acknowledged by parents and support staff. Their role was considered important by those who were interviewed precisely because the conflicts that arose in ongoing service delivery were often concerned directly with issues of individual self-determination and autonomy. Support staff reported that differences of perception often existed among residential staff, vocational staff, and sometimes parents, about the capacities of an individual, their independence, and the freedom of movement that should be granted them. Other conflicts arose among different staff over the kinds of activities that individuals should be pursuing, dietary issues, and the self-image individuals should be supported in creating.

Brokers were effective in mediating conflicts and issues that arose over these differences in perception. However, there was no mechanism, outside of initiatives by support staff and parents, to request the involvement of a broker when there was a legitimate need for their assistance in resolving conflicts. This left some individuals who were without family or other advocates no means, other than paid support staff, to initiate contact with a service broker. While initiatives by support staff were often an effective means for

activating brokerage, this was considered to be an inadequate long-term measure. It was sometimes the quality of service provided by the support staff themselves that was the reason for requesting a broker's involvement.

Notes

[1] The re-organization of the Ministry of Social Services and Housing has been an attempt, in part, to deal with the issue of generalized caseloads. The ministry now makes available social workers who specialize in planning for people with a mental handicap.

CHAPTER 3

ACCESS TO FINANCIAL RESOURCES ACCORDING TO INDIVIDUAL NEED

Those who were interviewed indicated that another important criterion of decision-making opportunity was that individuals be able to access funding for goods and services on the basis of their particular needs. In their experience one of the barriers to decision-making opportunity was that funding was often not allocated according to the particular needs of an individual. A number of parents had found that their son's or daughter's needs did not fit the criteria established for funding.

Based on the perceptions of those interviewed for this study, it appears that four criteria, other than that of individual need, have been used to determine individuals' access to financial resources. Many who were interviewed felt that the application of these criteria resulted in inequities in the allocation of financial resources. These criteria included crisis needs, age, diagnosis, and available program model.

First, social workers who were interviewed indicated that funding for individuals living at home with their parents is often restricted to those who meet the criterion of crisis needs. Funding has been targeted to individuals living in Woodlands in the sense that these individuals have been assured funding for the purchase of community services when the ward on which they are living has been designated for closure. Those living at home with legitimate needs for supports have not been assured access to funding according to their needs. As one social worker said:

> *... we are only able to do planning when there is a crisis emerging. More and more, the parents of my clients are elderly. Some will be in their 70s when they get community placements for their son or daughter. Others will have to wait until they are dying. Problems of funding limit the planning I am able to do.*

A second criterion for access to funding was that of age. For one individual who was interviewed for this study, the loss of his eligibility to receive "children's services" when he turned nineteen years old meant that he had to return to institutional care after he had been living in the community for six years. Funding for an appropriate alternative in the community was not made available until two years later.

A third criterion for access to funding was that of diagnosis. For some individuals included in this study, a diagnosis of "multiple handicap" meant that it was difficult to determine which was the lead ministry responsible for funding: the MSSH or the Ministry of Health. According to some of those interviewed, this has resulted in individuals spending long periods of time in institutional care while the jurisdiction for funding was determined.

The program model for which funding was targeted was a fourth criterion which had been used to determine access to funding. Some parents indicated that the available programs or services had not always met their sons' or daughters' needs. For example, one mother said:

> *When I went to social services to help me with my son they said, "We can't do anything because Victoria says we can't do anything". When I went to my local association to ask for help they said, "We can't serve your son". So, he had to go to an institution. It wasn't a problem of "lack of services" in the community. There were [services] and some individuals were able to arrange for them ... I didn't want "access" to the services that were there because they weren't prepared to serve my son.*

Another mother said:

> *I say to the social worker, "You're responsible to Victoria, you're not responsible to Jenny [daughter], to her best interests. You try to fit her into a program, a piece of legislation". Like local associations [who deliver services], they set up programs and try to fit people into them.*

Another problem that parents had when funding was allocated according to program models was that funding for a program could be cut or access to a program could be restricted. The consequence was individuals' legitimate needs could go unmet in the community. One parent said, in relation to her experience with this approach to funding:

> *There was a social worker involved before my daughter went to the Sunnyhill Hospital. She had arranged for a homemaker — this didn't work out. It was a totally ineffective response to the needs of my daughter and our family. They tell you what you need, they can't remain autonomous [from the ministry]. There just isn't enough flexibility with the social worker. It has to get worse before it gets better ... When my respite care was cut she said that I would probably get more attention if I took my daughter into a restaurant and beat her. But ... my husband left before I could get the respite.*

Individualized funding is not based on any of these four criteria. The principle criterion is that funding should be allocated first and foremost according to particular needs of individuals. In theory, then, it meets the criterion for decision-making opportunity identified by individuals and families — that funding be allocated according to individual need.

As indicated in Chapter One, certain features of individualized funding were implemented for all individuals served by the CLS. However, individualized funding has not been uniformly implemented. A few individuals in this study were found to have gained access to fully implemented individualized funding. Its features included individualized costing of required goods and services; funding allocated to a General Service Plan; and contractual status for individuals.

Most of those supported by the CLS received access to partially implemented individualized funding. Under these arrangements, individuals' GSPs were individually costed without funding being allocated to the GSP, and without provision of contractual status for the individual. The opportunity for individuals to make decisions varied somewhat under service funding depending on whether tendering procedures were used to select service providers.

FINDINGS

The study found the implementation of individualized funding through the CLS to have the following impacts:

- varied access to funding allocations according to individual need
- increased flexibility with fully implemented individualized funding

VARIED ACCESS TO FUNDING ALLOCATIONS ACCORDING TO INDIVIDUAL NEED

The mechanism put in place to allocate financial resources for the purchase of services determined whether funding was allocated according to individual need. Three mechanisms were in place for individuals in this study: (1) fully implemented individualized funding; (2) partially implemented individualized funding; and (3) costing of individual needs under tendering procedures.

Fully implemented individualized funding

Those few instances where individualized funding had been fully implemented were found to provide the greatest responsiveness of funding to individual needs, and the greatest decision-making opportunity for individuals and families. Determinations of need and costing of supports were made only after brokers had spent extensive time with the individual and family, developing their expectations and vision for life in the community, and accessing and providing information regarding funding and models of support. An individual and/or his or her family were then able to make decisions about the supports they wanted to purchase and the service providers they wanted to use. They were able to determine the contractual conditions on which services would be purchased and managed.

Partially implemented individualized funding

For most individuals served by the CLS, individualized costing of GSPs has been implemented. Individualized costing of needs, without funding allocations to the GSP, was found to provide some opportunity for individuals and families to make decisions. In these instances, the MSSH first established the parameters for service delivery. The CLS then carried out general service planning prior to final negotiations with the ministry. Although the parameters established by the MSSH meant that the individual would likely live in a three- or four-bed residence managed by the CLS, there was some scope for individuals and families to make other kinds of decisions. The scope of decision making varied between individuals and families. There was opportunity in some cases to make decisions about who the individual would live with; the staff who would provide support; the kind of day program or employment options that would be pursued; the way in which service delivery would be managed; or even where the residence was to be located.

Individuals and families were able to make these kinds of decisions in cases where the service broker was able to facilitate general service planning prior to negotiating purchase of service agreements with the ministry. Individuals were also able to advocate for themselves in the GSP process, or had close family or friends able to advocate for them. Decision-making opportunity was increased insofar as negotiations led to CLS services that were tailored to the particular needs and desires of individuals. However, while individual needs were explored with brokers through the GSP process, the basic model of support to be purchased (the group home), and the service provider (the CLS), were decided by the ministry and the CLS prior to commencement of general service planning.

Costing of individual needs under tendering procedures

The individual costing of plans carried out by service brokers under the tendering procedures for the downsizing of Woodlands was least responsive to individual need. Service brokers were not able to get to know individuals or families prior to submitting bids or proposals for service delivery. Consequently, it was more difficult for brokers to determine the nature and extent of supports that individuals and/or families wished to receive. Brokers suggested that purchase of service agreements which were not based on an adequate knowledge of the individual could result in unnecessary long-term costs to the ministry and to individuals. This was because agreements were difficult to renegotiate once they were in place. Yet the knowledge of individual needs and desires that brokers had gained after agreements had been made sometimes indicated that additional support staff was required. As well, some parents found the decisions that were made under tendering procedures without their involvement resulted in the contracting services that were not as responsive to their sons' or daughters' needs as they might have been. As one parent, whose daughter moved from Woodlands under the tendering process, said:

> *They [MSSH staff] kept telling me my daughter was going*

> *to be moving from Woodlands. I would wait a couple of months, and no word, so I would call again. It was the same story for about a year. And then, I find it's all been decided — the agency [delivering service], where she would be living, where she would go to a day program ... I had been very worried about my daughter leaving Woodlands because of her earlier treatment in a group home ... But it wasn't until I met some families with the CLS, and went to visit the homes their children were living in, that I began to see it could be different. And then I wondered why couldn't my daughter have this too? I'm not very happy with where my daughter is living. She's not very happy. But I don't think I can get the decision changed.*

INCREASED FLEXIBILITY WITH FULLY IMPLEMENTED INDIVIDUALIZED FUNDING

Those who were interviewed stressed that individuals' needs could change substantially over time. Their needs for support changed as they sought new opportunities for participation in training programs, or employment, or decided to live more independently. At the same time, if their disabling condition resulted in a progressive loss of functioning, levels of staff support had to be gradually increased, or new technical aids had to be introduced on a regular basis. For these individuals, "funding according to individual need" implied that funding would be allocated according to needs as they changed through time; that is, that there would be a flexibility in the funding allocations.

The study suggests that the greatest extent of flexibility in funding allocations is achieved under fully implemented individualized funding. However, there was such limited implementation of individualized funding in the case of those served by the CLS that there was no evidence of the possibility and process for renegotiating funding as needs changed.

In one example, a group home model of support had been purchased for a young woman from a non-CLS service agency. However, after a period of two years of receiving this form of residential support, the mother felt that the group home model might no longer be able to meet her daughter's changing needs. Further, she questioned whether the provider could respond adequately to the expectations and involvement of the family. As a result, she wanted to consider other kinds of arrangements that might include a mobile home on the family's property, twenty-four-hour staff supports, and the mother as manager of services. Because funding had been allocated to her daughter, and not to her service provider, she intended to seek renegotiation of the funding and contractual conditions with the Ministry of Health. In anticipating the process that would lead to a request for renegotiation of the funding allocation, the mother said:

> *We will meet, a group of us who have made long term, "for life", commitments to Christine. I'm not going to make the decisions. It has gotten too complex. We need to sit down, and as a group decide what Christine wants, and what we want for Christine, and how we can achieve it. Then I will call in the broker to help us put it into place ...*

Many of those who were interviewed felt that renegotiation of funding as individuals' needs and desires changed was not possible under a service funding approach except in extreme or crisis situations. So while partially implemented individualized funding provided for individualized costing of needs within the parameters of program models defined by the ministry, it did not result in funding allocations according to individuals' changing needs. To those who were interviewed, individualized costing was not as responsive to changing needs as a fully implemented individualized funding mechanism.

The inflexibility of a service funding approach was also evident in the disparity of funding levels between individuals with substantially similar needs. This disparity occurred because funding allocated in the early 1980s under the service-funded contracts with the CLS did not keep pace with the annual increase in costs for individuals. Only contracts negotiated to provide service to individuals moving from Woodlands in the late 1980s reflected these increased costs. Therefore, the funding allocated in 1989 to provide community services to those who had moved from Woodlands in that year was significantly greater than the funding allocated in 1989 for those who had moved to the community in the 1980s. In other words, the level of funding allocated depended only on when the individual left the institution and not on the changing costs or their changing needs.

SUMMARY

In the perception of many of those interviewed for the study, one of the barriers to decision-making opportunity was that funding had been allocated not according to the criterion of individual need, but according to other funding and program criteria. In their experience, this resulted in individuals receiving inappropriate services, or suffering the withdrawal of services, or sometimes receiving no services at all. Those interviewed felt that funding mechanisms that allocated funding according to individual need, and provided flexibility in funding as individual needs and desires changed, increased opportunities for individuals and families to make decisions about community supports and services.

The mechanism of individualized funding incorporates, in principle, both of these features. When fully implemented, those with access to this funding mechanism received access to financial resources on the basis of their individual needs as costed in a General Service Plan. This provided them the opportunity to expend those resources in accordance with the parameters specified in the GSP.

For those interviewed in this study, the service funding mechanism was not as able to achieve these results because the criteria for funding established by the ministry did not always fit with the needs and desires of individuals and families. Further, those interviewed felt that service-funded contracts could not easily be renegotiated in response to an individual's changing needs.

However, within the funding criteria established by the ministry, there was greater opportunity for individuals and families to make decisions under service funding where this mechanism was not implemented in conjunction with tendering procedures.

CHAPTER 4

ACCOUNTABILITY TO INDIVIDUALS

For those who were interviewed, decision-making opportunity was most fully realized when the decisions that were made about supports and services to be used were substantially accountable to individuals. Accountability to individuals for decisions made was, then, a third criterion for decision-making opportunity.

FINDINGS

Individualized funding and service brokerage were found to increase accountability to individuals in the following ways:

- provision of contractual status
- increased accountability of the service provider
- financial accountability
- facilitation of portability

PROVISION OF CONTRACTUAL STATUS

The experience of individuals and families interviewed for this study suggests that individualized funding is critical for a system based on accountability to individuals in decisions that are made. It served as a recognition that the process of moving to and living in the community was a negotiated one. The delivery of financial resources under a service funding approach was perceived to provide status in these negotiations only to the funding agency and the service provider. Fully implemented individualized funding, on the other hand, was felt to provide this status to individuals and, where they wished, to their close family or friends.

When individuals and their families had contractual status in purchase of service agreements, the process of negotiation changed. After decisions were made about the nature of support services that were required, one of the first steps was for the individual and family to negotiate the conditions which service providers had to meet. The conditions served as a kind of benchmark or set of criteria on which service providers would be selected. Negotiations with service providers then proceeded on the basis of the terms established between the individual and/or family, and the funding agency.

Contractual conditions for the purchase of the services that individuals and families wanted to be able to stipulate included:

- the nature and location of support services
- access by family and friends to the service setting
- procedures for individual planning
- quality assurance and monitoring

Nature and location of support services

Some of those who were interviewed indicated that the opportunity for individuals and families to specify the nature and location of support services would ensure that legitimate needs would be met. It would ensure that individuals would not "fall through the cracks" in the service system simply because available programs were not structured to respond to their particular needs. The opportunity to specify, contractually, the kinds of supports that were required also provided a guide to the funding agency and providers in adapting programs and services.

In one example of individualized funding discussed above, the mother who was carrying out the negotiations on behalf of her daughter, Christine, specified that the residence to be purchased had to be within five miles of both the school and the hospital. This was required because of the need for quick access to emergency assistance and, because of Christine's condition, to limit any travel time in a vehicle. Arrangements also included the condition that Christine would receive funding for an attendant who could be with her when she was at school, or at home on the days she was unable to go to school, and during transit to and from school.

This latter condition was one that, initially, could not be met within the eligibility criteria for funding of attendants through the Ministry of Health's Services to the Handicapped Division. While the ministry could cover costs for an attendant at home, it could not cover costs for the attendant at school. The attendant at school could be covered under the Ministry of Social Services and Housing's Chance program. This program was implemented to provide funding for personal attendants to assist children with a handicap in the classroom. However, attendants funded under this program could not assist in transit or at the child's home. The commitment by the ministry to an individualized funding approach meant that the onus was on the Ministry of Health and the Ministry of Social Services and Housing to work out inter-departmentally how to meet the condition specified by the parent for an attendant that followed Christine whether at school, in transit, or at home. In acknowledging approval for funding, a Ministry of Health official wrote, "The challenge will be to establish an appropriate payment mechanism that recognizes jurisdictions." Contractual status meant that the individual did not have to fit in to the Ministry of Health's established program criteria, or the MSSH's Chance program. Rather, contractual status for the individual and family meant that the two ministries had to determine how they would work out arrangements in order that individual requirements and conditions could be met.

Access by family and friends to the service setting

Those who were interviewed also wanted to stipulate conditions that ensured access to the service setting by family and friends. Parents felt that in the past, service providers had restricted their access to the service setting. Service providers had responded in a number of ways when parents requested uninhibited access to the service setting and/or participation in all decision making concerning their son or daughter.

One response by providers was to decide not to deliver services to an individual when the parent insisted on their own active involvement.

Another response was to contract the "non-interference" of parents through a formal agreement imposed by the provider. The parents felt that their compliance was necessary if the provider was to continue delivering services.

In a third situation, a parent informed a residential provider that her involvement was necessary in making decisions about the care of their daughter. However, the parents were not invited to social functions at their daughter's home, were not told about medical problems until after decisions had been made about how to deal with them, and the parents felt they were not welcome at the residence.

In a fourth instance, the parents were requested by an official with the MSSH to make their child a ward of the state if they wished to receive a community residential placement for their son. The parents felt that this was a totally unacceptable condition for receiving services as it would restrict their access to their son, and that it would unjustifiably limit their participation in the decisions made about his care. After much negotiation, this request was dropped and the child did receive services.

Because of the various ways in which families felt they had been restricted from the service setting and from the decision-making process, they wanted agreements which would prevent such occurrences. Specifying contractually that access was a condition for an agreement with a service provider was seen as one solution. In one instance, parents negotiated unrestricted access to the service setting at all times. This was entered as a condition of the contract through which the service provider received funding. Involvement of parents in all decisions concerning their daughter's care was also specified as a contractual condition.

It should be noted that the CLS has ensured unrestricted access by family and friends to its own residential and vocational service settings not by virtue of individual contractual arrangements, but rather by virtue of a policy decision on the part of the agency. This requirement has been communicated to residential and vocational support staff through staff training program and through service brokers when they have met with support staff to implement or review GSPs. Contractual status has not been required in order to access the service setting in these cases. However, some of those interviewed felt that contractual status would ensure that the provider would be accountable for making the service accessible to families. It was believed that such accountability would address the barriers that some families had experienced.

Procedures for individual planning

Some of those who were interviewed felt that the way in which individual planning was managed in ongoing service delivery should also be subject to conditions specified by individuals and families. Their concern was that the formalized Individual Program

Planning (IPP) process that was often used by service providers did not ensure accountability to the individual. Some support staff felt that IPPs tended to identify objectives that required change and adaptability by the individual, and did not encourage adaptability by the provider. One residential support worker suggested:

> *IPPs tend to set these folks up for failure. If they can't meet their objectives they fail.*

In reference to the IPP process used when her daughter moved under tendering procedures to a non-CLS residence in the community, one mother said:

> *I don't have "goals" for my daughter. I just want her to be happy ... We have sat down with the social worker, the agency, the psychologist, to define "goals". I stressed that one of the most important things to Maria was her music. That "goal" was never written into the record of the meeting. I want her to have her own room, to have a nice sound system. I want warmth from the staff. I want them to like Maria. Those are the goals. But they can't seem to deliver on them. There is a hygiene program and social events program. These are important. But they don't mean anything if Maria isn't happy. And she isn't. She is more and more upset, having more and more tantrums ... They seem to have a "behaviour" program. Maria has said one staff member said he was going to "tie her in the hard chair", and that she was going to go back to Woodlands if she didn't behave. I don't know if it's true. But she is very intimidated by him. It's a real concern for me. I'm terrified about raising these issues because I'm afraid they will take it out on Maria.*

For this parent the IPP process did not secure accountability to her daughter. From her perspective, the process resulted in the implementation of individual programs by the provider which, in some cases, seemed to undermine accountability to her daughter.

In the case of individualized funding reviewed above, the mother specified that IPPs were not to be used as the planning tool in the delivery of residential services. Rather, the planning process in ongoing service delivery was to include the use of the GSP as a reference document, the mother's involvement at all staff meetings where her daughter's support was to be discussed, and the involvement of a broker at her request. For her, the emphasis in ongoing service delivery was not on developing individual programs, but in working on a daily basis to ensure that her daughter remained at the centre of the process. She said:

> *I don't want total agreement with staff or anybody all the time because then I have control. I want to know that the support staff are keeping my daughter at the centre of what's going on. I want a consensus that she is the focus, but then we can have differing opinions. I need their different views.*

In this case, the support staff also felt that the GSP was a tool which could ensure that the individual was at the centre of planning in ongoing service delivery. As one support staff said:

> *This home is different than the other homes. All the other residences [managed by the agency] use some form of IPP. Here, the only document is the GSP — it outlines all the crucial information. In other homes they don't have a GSP so the staff proceed by trial and error ... This house is like a "mole" in the larger organization. It has been something of an issue with the agency because of the different procedures [no IPPs], her mom's constant input and complete access to the home, and the total focus on the individual. The other residences are much more "group homes" with twelve people per residence.*

The research found that individuals and families vary in the type of individual planning process they want in ongoing service delivery. Despite this variation, they felt that it was the opportunity to determine how planning would be carried out that was important in increasing accountability to the individual and family. The interviews suggested that individuals and families want to be able to determine the following aspects of the individual planning process:

- the kinds of decisions a service provider would address or be involved in, and those they would not be involved in (i.e. the staff supports to be used, diet, dress, individual programming, leisure activities, behaviour management, skills development, sexual behaviour, development of personal friendships);

- others who would be involved in making the decisions;

- the extent and nature of involvement of family and friends;

- the methods to be used in individual planning in ongoing service delivery (i.e. individual program plans, review of the GSP, twenty-four-hour plans, case conferencing, staff meetings, informal approaches).

Quality assurance and monitoring

Another set of conditions which families wanted to be able to specify were those related to procedures for quality assurance and monitoring of service delivery. However, there was wide variation in the kinds of quality assurance and monitoring that they perceived to be required.

Those who were interviewed felt that all individuals did not require the same monitoring supports. Some individuals played this role on their own through their own capacity as self-advocates. Many of the parents interviewed in this study provided the monitoring function themselves. By visiting and spending time with their son or daughter in the places they received services and supports, parents were able to carry out their own informal assessment of service delivery. Some parents who were interviewed stressed that the design of monitoring should be guided by an individual's particular needs and requirements for monitoring.

INCREASED ACCOUNTABILITY OF THE SERVICE PROVIDER

The opportunity for individuals and families to specify the contractual conditions that service providers had to meet was found to be one means of increasing accountability to individuals.

This contractual accountability to the individual was found to have a direct impact on support staff employed in residential and vocational services. Those employed in CLS and non-CLS services indicated that, for them, individualized funding and service brokerage resulted in three lines of accountability:

- to the individual and the family, and the specified conditions of the GSP and service contract (where individualized funding is in place);

- to the service provider (where they are employees), to deliver services within the budget guidelines and philosophy of the organization;

- to the broker who may be involved infrequently but is recognized to have influence over the nature and direction of services for individuals.

Support staff indicated that their ability to manage these lines of accountability determined the extent to which they were able to ensure accountability to individuals in decisions on ongoing service delivery. They also indicated that conflicts could arise between these accountabilities.

In cases where individualized funding had been implemented the immediate impact was to create a contractual accountability of the provider to the individual. Contractual accountability intensified the conflicts for support staff. It changed how the organization and the support staff perceived their relationship to the individual and family. A staff member employed in a non-CLS residence expressed the tensions in these terms:

> *I feel I'm working for a number of actors and I'm not sure who I'm ultimately responsible to. My administration tells me I'm to follow this organization's operational approach. But this home is different than other homes run by the agency because of its individual focus. The administrator is concerned with overall management at a grand scale. Fine. He's struggling for control. But I'm struggling for Christine's identity ... We're trained by this organization. But we're not trained for her mom's daily involvement. And as staff we don't have much in common with staff in other homes run by the agency because of the way we operate here. They don't understand us. So there is an issue of staff support. We need ideas on how to manage this. We need ideas on how to widen Christine's circle of friends and personal supports so she can become more connected in the community.*

Support staff also perceived some responsibility to the broker given that the broker was the individual's agent. Staff raised a number of questions regarding this responsibility. To what extent were staff to respond to the direction of brokers? To what extent did staff's implicit or explicit contract to individuals override, at the broker's initiative, their responsibility to their own employer, the service provider? One support staff perceived the impact of the broker in this way:

> *I have a sense that parents are able to be involved because of the broker. I thought at first that the broker should be more involved on a day-to-day basis in the running of the home. But I see now how the broker passes the needed information to the mother so that she can be involved. If she wasn't here, I would expect the broker to be more involved ... However, I don't know where my Board and administration fit into the brokerage system. The organization doesn't know what expectations we should have of brokerage. There are a lot of questions.*

The administrator of a non-CLS residential service agency acknowledged the tensions that multiple accountabilities introduced for the service agency and support staff. However, he also noted that this was simply an issue that needed to be addressed. The fact that tensions existed did not undermine the merits of individualized funding or service brokerage While the issues had to be addressed, the commitment to increased accountability to the individual had to be maintained:

> *I have felt for a long time that for any program to have any degree of integrity in terms of the service provided, there needs to be a lot of input from the individual. This can be a thorn in our sides. As an administrator, I recognize the complexity in all of that, the uncomfortableness. There are two sides to me. One is, I would like to see something very efficient, a kind of benevolent dictatorship. But this kind of thing ... [brokerage and family involvement] introduces a democracy in the best sense which of course is less efficient. But I am convinced that for growth to take place at the level of the service provider, there needs to be that struggle. So I understand, but I have struggles within me ... the real world, budget deadlines.*

CLS support staff also expressed commitment to ensuring accountability to the individuals they supported. They indicated that the CLS had been effective in communicating to them the importance of such a goal. However, they also believed that accountability to the individual was not accomplished on their part only through a sense of personal commitment. They felt they lacked the organizational resources to implement such a focus. They indicated that such resources include:

- job security and a level of income which can encourage support staff's long-term involvement and career development;

- performance appraisal procedures that are able to recognize and value support staff's contribution to focusing the service on individuals, and increasing accountability;

- a responsiveness by the administration to negotiate with staff about how to manage services to meet needs and provide decision-making opportunities;

- a training and development program that assists staff in transforming the philosophy into concrete strategies in "everyday decision making";

- an opportunity for staff, in various CLS operations, to exchange ideas among themselves about how to manage services within the context of the philosophy of CLS and the directions being set by individuals and families. This has begun to happen with the organization of staff groupings on a regional level.

The research suggests that while fully implemented service brokerage and individualized funding established conditions for increased accountability to the individual in service delivery, these mechanisms were not by themselves able to secure that accountability. There are other factors related to the delivery of services which also determined the extent of accountability. These included the availability of a supply of support staff committed to such a goal; the level of resources allocated to compensating and developing support staff; and the human resource policies of the service provider which provided the incentives or disincentives for support staff to implement greater accountability to the individual.

FINANCIAL ACCOUNTABILITY

Some of the parents who were interviewed indicated that financial accounting on an individual basis would encourage greater accountability to individuals in ongoing service delivery. These parents wanted some recognition that a service provider was spending dollars allocated for an individual's income assistance, and for his or her residential and vocational supports. Financial accounting to the individual and his or her family was seen, then, as one means to review the financial decisions the service provider was making on the individual's behalf.

The CLS has attempted to provide such accounting by tracking the expenditure of dollars targeted (but not allocated) to individuals under individually costed GSPs. The system currently in place at the CLS has not been used on a consistent basis to provide individual financial statements for expenditures made on individuals' behalf. Some parents expressed frustration with not being able to access the accounts in order to see how the funding allocated to their son or daughter has been expended.

The CLS has not been able to fully individualize the accounting of expenditures primarily because of funding arrangements with the MSSH. Most of the funding for CLS services has been allocated by the government under "service-funded" contracts. Because more recent CLS residences have been much more richly funded than those the ministry funded in the early 1980s, the CLS has, to some extent, pooled the dollars from across its service system. This has been necessary in order to ensure that the needs of individuals living in the more poorly funded residences were adequately met. As a result, it has not been possible for the agency to maintain a strict accounting relationship between the funding negotiated for an individual and the expenditure of that funding.

FACILITATION OF PORTABILITY

Portability within the service system, or the opportunity for an individual to change the providers who deliver his or her support services, was identified by some individuals and families to be an important indicator of accountability to the individual. It was also identified as a critical area of concern by service brokers, CLS administrators, and MSSH officials. Lack of portability was found to be a problem in cases where individuals wanted to change service providers, or where providers withdrew services from an individual.

Some of the individuals supported by the CLS experienced this problem. In one instance, a young man was removed, with some of his belongings, from the residence in which he was living. His mother recounted the event this way:

> *We [parents] were ... asked to sign a contract saying that we would agree with programs and would agree not to interfere in the service. What could we do? We needed the service. One of these programs involved giving Gerald tokens for good behaviour. When he had enough tokens he*

> *could have a friend over. But who should have to buy friends with tokens? And they did stick to the program to remove my son if he had a fight with his roommate. But it happened when my husband and I were out of the country. They sent him to a men's shelter on skid row.*

The CLS has also been requested by families or the MSSH to deliver vocational services to individuals because their previous service providers had decided they would no longer deliver services. It was felt by some of those interviewed that providers made these decisions on the basis that "behaviours" were too difficult to deal with, or because the individual appeared unwilling to abide by the rules of the work setting. For example, one CLS vocational support staff member said:

> *Henry was in [a sheltered workshop] for ten years. In the fall he was kicked out. They said they wouldn't have him any more so brokerage got involved. Workshops seem to reject people that don't fit. Our approach is to fit programs around individuals on their own terms. When we got the contract to work with Henry he was pretty abusive. He fought every morning. Now over the past few weeks he's started to take some initiative. He's not working as hard as he can. But we give him the space to say no. We're not going to fight with him.*

Another CLS vocational support staff member who used to work in a sheltered workshop felt that the workshop environment itself resulted in behaviours that individuals were then fired for. She said:

> *I remember having to deal with behaviours that resulted from the workshop environment. Now I work in the day mod with some of them who were fired for their behaviours. Their behaviours are now non-existent.*

When individuals left on their own or were forced to leave, they were often without means of acquiring new services. In some instances, the service provider retained their funding base and filled the vacancy left by the individual. Until another program was willing to provide service, or the individual was able to access additional funds, he or she was left without day programs. In some cases, individuals had to wait many months.

Because there is such limited implementation of individualized funding, it was not possible to fully assess the impact of this mechanism on facilitating portability within the service system. This mechanism may facilitate portability insofar as individuals' contractual status enables renegotiation of conditions of service and contractual arrangements as needs change, or as the service becomes inappropriate or inadequate.

However, the research suggests that there are other important factors besides contractual status that impinge on the opportunity for individuals to initiate change. It could be argued, for instance that because the CLS now manages thirty homes for individuals, the agency should be able to facilitate portability within their own substantial "closed" market of housing and support services. There is demand by individuals for such portability. The reasons they have given for wanting to change their residence include: incompatibility with the people with whom they lived; a desire to live in more independent situations; or a desire to live closer to their families. However, there are three factors which limit portability even within the CLS centrally managed market.

First, there is a lack of vacancies within the residences supported by the CLS. A second factor is related to the issue of equity and fairness. The funding allocated to provide service to an individual is tied to a particular residence, and, as indicated above, there is substantial disparity in the levels of funding between CLS residences. This disparity in funding is not due to variation in individuals' needs, but to other factors. Such factors include: the year the funding agreement for the residence was negotiated with the ministry; whether or not administrative funding was included in the contract; and the limited annual increases for residential agreements that were negotiated in the early 1980s. The level of funding allocated on behalf of an individual is not renegotiable simply because an individual wants to move to another residence that may be funded at a substantially lower level than the one they move from. This raises issues of equity and fairness if one level of funding was initially negotiated for an individual and the funding allocated was then reduced simply because the individual left or moved to another location.

A third factor not resulting from the impact of the service funding mechanism was that the information flow between individuals, support staff, brokers, and CLS administration was sometimes inadequate to respond to an individual's expression of interest in changing their living arrangements. This issue is related to variations in access to the assistance of the broker and to the inability, in some cases, to activate brokerage.

SUMMARY

Individualized funding and service brokerage, compared to the conventional planning and funding mechanisms, were found to increase accountability to individuals and their families. Greater accountability was achieved through the contractual status provided to individuals and their family or friends in the purchase of service agreements. With this status they were able to determine the conditions on which services would be purchased; who the service providers would be; and how the services would be managed.

Those who were interviewed suggested that individuals and families wanted to be able to determine contractual conditions regarding the nature of supports to be purchased, the access by families and friends to the service setting, the procedures for individual planning in ongoing service delivery, and the procedures for ongoing monitoring and quality assurance.

Support staff indicated that the contractual status provided to the individual, the access to the service setting negotiated by the family, and the presence of a broker have had a substantial impact on increasing accountability to the individual. At the same time they felt that, as support staff, they were often asked to ensure accountability without the adequate organizational resources, compensation, or back-up support. They stressed that increased accountability to the individual requires more than personal commitment on the part of support staff. It requires increased organizational resources in the form of compensation, job security, appropriate performance review procedures, and a staff development program which provides concrete strategies for increasing accountability to the individual while providing a high quality of service.

Portability within the service system was identified as an important condition for accountability to individuals in decisions about service delivery. The service funding mechanism has acted as a disincentive to portability because funding was attached to a residence and not to an individual. Individualized funding may increase portability if it provides individuals with the opportunity to renegotiate conditions of funding and service contracts. However, factors other than the funding mechanism were found to impinge on increasing portability. One factor was limited vacancies in CLS and other community services. A second factor was that the CLS has had, to some extent, to pool funding allocations from across its service system. This has limited financial accountability to the individual, and has been a disincentive to portability. A third factor that limited portability was the difficulty in accessing brokers to assist in renegotiating funding or service delivery where individuals did not have family or friends to advocate for them.

CHAPTER 5

AVAILABILITY OF A RANGE OF COMMUNITY-BASED ALTERNATIVES

The availability of a range of community-based alternatives for supports and services was identified as another criterion of decision-making opportunity. Accountability to individuals was not achieved if there was not an adequate range of alternatives from which to make decisions about support and service delivery. Although many of the parents who were interviewed had decided at one time to place their son or daughter in institutional care, they did so because they could not find other alternatives. The lack of community-based alternatives had forced them to make a decision which, rather than reflecting accountability to an individual, appeared to undermine such accountability.

When individuals first started moving from the institution back to the community, arranging for community service providers presented a continual dilemma. Since the commitment was made to downsize institutions and to provide community-based supports to individuals with even the most challenging needs, more specialized service providers have become available.

While there is an increasing number of specialized services, generic alternatives are less available. Having helped their sons and daughters move out of the institution into specialized services, some parents now want to see them move out of specialized services to take advantage of the non-specialized residential, vocational, educational, and recreational supports more generally available.

FINDINGS

Partial and fully implemented individualized funding and service brokerage were found to have the following impacts on the availability of community-based alternatives for support and service delivery:

- incentives for increasing the range of options
- facilitation of resource development
- access to generic services
- increasing the range of service providers through separation of support services.

INCENTIVES FOR INCREASING THE RANGE OF OPTIONS

Some parents who were interviewed believed that there was a need for a wider range of available program models. Many stressed that without a wider range it was difficult for planning and service delivery to respond to the diverse strengths, needs and goals of individuals.

One mother found that the program models which the government agreed to fund had limited her own vision of possible models of support for her son:

> *We had a negative experience in trying to establish a facility for our son outside the institution, and then discovering that because of the model that we chose, all we did was create a mini-institution. And that is because [the model] was determined, it was based, on a label. We developed these things [group homes] because of a label ...*

The impetus for the models of residential support delivered by the CLS came from the parents originally involved in the Woodlands Parents Group. Parents stressed that individuals' homes were to be small-scale, for three or four individuals. They believed that their son's or daughter's homes should not have staff offices in them, because the families felt that people without labels did not have staff offices in their homes. This model differed quite sharply from what some parents perceived as the "large and institutional group homes" otherwise available for individuals in the community.

Three- or four-person residential arrangements, while once a major innovation for individuals who require twenty-four-hour supports, are now more and more common. They are the model of support that the ministry often purchases under service funding for those who require twenty-four-hour supports.

While this model has become the mainstay of community residential support, its exclusive use was questioned by some parents who were interviewed. Some wanted the opportunity for just two individuals to live together; others wanted individuals to own their own homes (either individually or cooperatively); and some parents wanted their son or daughter to live in quarters attached to the family's residence. However, the service funding mechanism did not appear to provide incentives for developing this diversity of models.

Individualized funding can "technically" provide incentives for greater diversity in models of support services by tying their development to individual need and demand. However, because implementation to date has been so limited, it is too early to tell the extent to which this funding mechanism would encourage this diversity.

FACILITATION OF RESOURCE DEVELOPMENT

The range of support and service provider options has been affected to some extent by the procedures for resource development that have been implemented under service funding. The MSSH has chosen, through tendering and other procedures, to manage the supply of a relatively limited range of services rather than to develop and diversify services in accordance with demand. Management of demand would require that the development and purchase of services be tied more directly to the needs and desires of particular individuals.

Through individualized funding and service brokerage the CLS has sought to make a closer link between individual or general service planning and resource development. In the CLS model, the GSP is to be the basis of funding and development of community resources. Where the GSP has been individually funded, brokers have played a role in facilitating the development of resources. Their role has included staff training and consultation with a provider in developing or adapting a service according to an individual's GSP. Brokers have been able to provide information and expertise to the individual, family, and the service provider in putting the supports identified in the GSP "on the ground".

Brokers' assistance in facilitating resource development has been felt not only by individuals and families, but by service providers as well. Some service providers who were interviewed found that the brokers were able to play a role in assisting them to develop the supports they delivered. They identified the distinctive feature of the broker as his or her ability to orient resource development around the individual. One service provider commented:

> *The broker was very important in getting Norma established in the community with the right supports. He stressed that she had rights and that we had to maximize our efforts to provide her with the supports she needed. He was the facilitator that brought the whole thing together. He asked, "What are the moral obligations of the school, the service provider, society?" He also asked, "What are the ethical responsibilities of government?" He acted on the recommendations of the mother, the school, and the doctors.*

Another service provider also commented on the role of the broker in working with service providers to develop resources. She noted that the autonomy of the broker was critical if they were to play this role, and commented:

> *Listen, a social worker couldn't have done what a broker did [in facilitating resource development among a set of service providers]. When the social worker walks in, the red flags go up.*

Individualized funding provides a mechanism for specifying certain standards and conditions for service delivery in an individual's GSP. In some cases, brokers have been able to use these standards and conditions as a guide in facilitating resource development. The opportunity for the broker to play this role, however, seemed to depend on the extent to which the GSP was the basis for funding and contractual arrangements. To the extent that it was, service providers were bound to meet the standards and conditions as specified in the GSP. Brokers were seen in these instances as an important resource in assisting the provider to meet the terms of the GSP.

ACCESS TO GENERIC SERVICES

Barriers in access to generic services (recreation, education, housing, etc.) were identified as an ongoing concern by many of those who were interviewed. The research found three factors that tended to limit such access.

First, access to generic resources requires that support staff in specialized services actively create opportunities for individuals to participate in a wide set of community activities. Some of the parents and CLS support staff who were interviewed felt that support staff were hindered in this role by their available time, job definition, perception of individuals' needs, attitudes about community integration, and their level of expertise.

Second, individuals, families, and support staff have found that generic education, employment, recreation, and housing resources present barriers to access. For example, one woman interviewed for this study was denied access to a publicly funded housing cooperative because she was considered "unsuitable" for participation in that housing environment.

Third, individuals, families, and support staff have found that accessing generic resources is more than "getting through the door". Even if a generic provider is willing to make facilities or services accessible, they often require assistance in facilitating integration. It may require staff training, architectural changes, and increased flexibility in programs and operations. Assistance to the generic provider in making these adaptations is often outside the role and expertise of support staff in specialized services. One parent saw the dilemma this way:

> *It's not that we don't need "specialized" support staff to help our sons and daughters do what they want to do whether it's swimming or training for the marathon, or going to church. What staff need is the assistance to take that step back, the step back from ownership of people's lives ... The support staff need the generic service back-up. But the problem is that by themselves the staff can't seem to get Derek into the fitness club, or Marlene into the recreation centre. What do they do when these places refuse to open their doors? The reason they refuse is because they don't know what to do when they do open their doors.*

Service brokers were found to play a role in providing this back-up support to assist in increasing access to generic services. One mother who was interviewed spoke of the process of negotiating access to the generic or integrated educational system, as opposed to a segregated school:

> *One of the decisions we want our son to be able to make is to use generic services and not all these specialized programs ... My son came out of Woodlands into a segregated school situation. It was my efforts to get him into an integrated situation, with the help of the broker, that helped to break the barriers down. I knew full well, and the principal knew full well, that if they accommodated Jonathon then they would have no recourse but to accommodate everyone because Jonathon's needs were the greatest in the segregated setting. Without the moral support of the broker I wouldn't have been able to do it, to have the courage. The broker was able to help us to know when it was best to go alone [to meet school officials], with another family, or when it was best for him to go with us. He would arm us with information that we might need in a meeting; would meet with the principal and a teacher, with us, on our behalf, if that was necessary. We were able to go through a process of strategizing, and the broker was able to offer help to the education system to make it happen. I don't know if it would have happened without the broker.*

Factors discussed above which affected access to the broker (limited funding, lack of family and friends able to advocate) were also found to affect the extent to which service brokers were able to assist individuals in accessing generic services.

SEPARATION OF SUPPORT SERVICES

For the individuals represented in this study, one or sometimes two service agencies delivered all residential and vocational supports. Individuals and families did not have the opportunity to make decisions to contract a wider range of service providers with the funding allocated on individuals' behalf. This monopoly on the provision of supports by one provider may limit the availability, diversity, and accountability of support services and service providers that individuals can access.

One contractual arrangement is not necessarily required in order to deliver the variety of needed supports. Distinct residential supports, for instance, may include the actual housing unit or resource, the maintenance of the physical plant, an individual's support staff or attendant care delivered at home, and administration of contracts and financial accounting. Individualized funding would give the individual the power to contract each of these supports separately.

SUMMARY

Because of the limited implementation of individualized funding, a systematic assessment of its impact on the availability of the range of community-based supports and services was not possible. However, the research suggests that this funding mechanism does hold the potential to increase the range of available options by tying resource development to the funded GSPs of individuals. Resource development is thereby managed through a demand-oriented approach rather than the current supply-oriented approach.

Service brokers were found to increase options through their assistance to individuals, families, and service providers in adapting both specialized and generic services to more adequately meet the needs and wishes of individuals. The broker was able to facilitate resource development by using the GSP as a document to guide service providers in adapting and developing resources. Factors affecting access to service brokers shaped their effectiveness in facilitating resource development. As discussed in Chapter Two, these factors included limited funding, administration of funding (service funding or individualized funding), and availability of family and friends able to advocate for an individual.

Individualized funding appears to hold potential to increase options by facilitating the separation of support services. Residential support services might be separated in a number of ways. For example, attendant care, property management services, general accounting services, and the housing unit, can all be envisaged as distinct supports, each delivered through separate contractual arrangements.

CHAPTER 6

RECOGNITION AND STATUS FOR CLOSE FAMILY AND FRIENDS

Another criterion of decision-making opportunity for individuals was that their close family and friends be given recognition and status in decisions about the nature of supports, service providers to be used, and ongoing service delivery.

Many family members who were interviewed for this study wanted more than involvement in decision making, and more than a recognition that they could be strong advocates for an individual. They also wanted status in the decision-making process when individuals designated them to play such a decision-making role. Those who were interviewed felt that although individuals might not be able to verbally designate status to family members, individuals were able to express implicitly or explicitly whether they wanted their parents, or brothers and sisters, or close friends to be a part of the decisions that were made. Families wanted their status to be secured for two reasons.

First, they indicated that where an individual designated such status, government and service providers should honour his or her right to make this decision. Second, the perceptions of family and friends were not necessarily bound by medical or professional assessments. Their understanding of an individual's need was informed by their "vision" and expectations for an individual's life. They felt that this vision developed from a shared history and relationship. They believed they were in a unique position, therefore, to make decisions about an individual's community supports where an individual was unable to articulate this.

FINDINGS

Individualized funding and service brokerage were found to have the following impacts on providing recognition and status to close family and friends in the decision-making process:

- emphasis on the knowledge of family and friends in decision making
- increased status in decision making.

EMPHASIS ON KNOWLEDGE OF FAMILY AND FRIENDS

Many of the parents who were interviewed felt that, in the past, the definition of the needs of their sons and daughters had been based principally on medical and professional assessments. They felt that these assessments tended to isolate the definition of needs from the exploration of a vision and expectations for an individual's life in the community.

The emphasis on professional needs assessment was perceived to reinforce the labels attached to a person. Some of those who were interviewed felt that professional assessments and the labels associated with them also resulted in a perception that individuals were "problems" who required the expenditure of resources in order to contain or solve the problem. One parent whose son had been in and out of hospitals and group homes for a number of years said:

> *In the regular bureaucracy, professionals look at behaviours. They don't ask why a person behaves in a certain way. They don't ask how we can turn behaviours around. When you see the reports of individuals coming out of institutions [profiles of need], they only say what can't happen. They don't look at the positives and at the weaknesses, or at things that can be changed. They only see the barriers.*

Many found that it was difficult to get past the definitions and labels that had been imposed in the assessment of individual need — assessments that had been the condition of funding and service delivery. The challenge to parents was to see their son or daughter as a person who could make decisions, and who could lead a full, involved, and satisfying life as a valued member of the community. One mother who reflected on this challenge in her own family said:

> *We changed our attitudes by asking what we expected for our other children. What did we want for them? And then we asked why couldn't we have the same for our family member who has a handicap, or who has a label? Why are we expecting all this specialized stuff? And that's what helped us to get on with it. What we came to want was what we wanted for ourselves, what is in place for ourselves in the community.*

For many parents, learning to change their expectations resulted most often from their interaction and mutual support with other parents. As one mother said, whose son had lived in Woodlands for a number of years before returning to the community as a young man:

> *I was able to "dream" because of my interaction and relationships with other families. When I caught onto a dream for my son it just turned me around completely. I know now how important it is to talk with families. The brokerage helps us to put goals into place, but the initial dream comes from being able to share our experience with other families.*

Some of those interviewed found that service brokers were able to ensure that the personal knowledge of families and friends was a foundation for the GSP. Brokers did this in two ways. First, a number of parents felt that through the GSP process the personal knowledge and vision of the family or close friends were recognized by the broker to be essential in defining individual needs. Many found that the broker validated the family's own knowledge and views. They indicated that this was unique in their experience with professionals. Second, some of those interviewed felt that the broker encouraged family and friends to expand their perceptions and expectations of the individual. One parent said:

> *What attracted me most about the CLS was their philosophy—focus on the individual. They would build a service around my son, Jeff. The broker was the one who said, "I think we can do this". He encouraged us to dream. The family starts to think that their family member can do things. The broker gets people to look at the positive — how to build on potential. This helps parents to get a more objective view.*

The study found three outcomes resulting from the broker's emphasis on the knowledge and expertise of families.

First, when families and close friends were actively involved in the GSP process, they assisted individuals in identifying personal goals and hopes. They assisted through their ability to interpret, clarify, and reinforce individuals' wishes.

Second, close family and friends brought to the planning process their own expectations for an individual's quality of life — expectations based on their personal history and relationship with an individual. In doing so, they provided a context for perceiving the individual that might not otherwise have been available to the broker or service provider.

Third, family and friends assisted in identifying and locating community resources, interpreting individuals' needs so that appropriate resources could be selected, and, where necessary, making decisions about service delivery. They were also able to advocate for the development of resources when these were not available.

INCREASED STATUS IN DECISION MAKING

Through the GSP process service brokers have provided status and recognition to families in defining individuals' needs for support. However, the status of the GSP in funding and service delivery has determined the extent to which the knowledge and expectations of families has been a basis for making decisions.

Where the GSP was funded under an individualized funding approach, individuals and families could make decisions because they were able to specify the contractual conditions upon which services would be delivered. The tendering procedures afforded the least recognition and status to families in decision making. Under the tendering procedures some families did have the opportunity to suggest who the individual would live with, and they could suggest additions or deletions to "profile of needs" prepared by ward staff and the social worker. A government document laying out these procedures also specifies that "parental involvement can only be minimal" in the selection of service providers or "contractors". The document also states that once providers are selected and contracts are negotiated, it is expected that parents will become very involved in decisions about how the service will operate.[1] Many who were interviewed felt that the tendering process denied status and recognition to families in the decision-making process.

The research found that three reasons were used to justify restrictions to families in decision making when their son or daughter was leaving the institution.

First, there was a genuine concern expressed by some government officials who were interviewed that downsizing at Woodlands should be carried out as quickly as possible. One senior official in the MSSH said in an interview that "we don't have time to go the brokerage way". There was a belief on the official's part that involving families, through the GSP process as it was managed by brokers, would require time that could not be afforded in a downsizing process. Another official believed that the government commitment to deinstitutionalization could be undermined if individuals remained in the institution for too long. The commitment would be undermined in the face of other interests, including those of labour unions and families opposed to closure. In this argument, limitations on family involvement could be justified in order to realize a more important goal for managing closure — that individuals be moved to the community before political commitment waned.

A second argument for limiting the status of families in decision making was implicit in the principles of accountability for managing the closure. The MSSH document on Community Placement Planning identified the principle that accountability to the taxpayer was required. The document defines tendering as a set of procedures which meet the government requirement that:

> *... before taxpayers dollars are committed to a service provider, all interested and qualified service providers have been given an opportunity for consideration. Also that the service provider best able to provide the service and offering a reasonable or acceptable value for the money to be spent is selected.*[2]

While the tendering process may to some degree result in accountability to taxpayers, it does so at the expense of any accountability to individuals and families, who are also taxpayers. Further, there is no evidence to suggest that greater accountability to individuals would necessarily result in less efficient allocation of public dollars. There is some anecdotal evidence to suggest that, on the contrary, individualized funding can result in more efficient allocations. This is because it limits the under- and over-serving of individuals, both of which can result in unnecessary long-term costs.

A third argument for restricting families from the decision-making process was implied by government officials in their concerns that some families were not necessarily in favour of closure, and that some opposed it vehemently. The concern expressed by one government official was that these families could impede the progress of institutional closure and that they might undermine the political commitment to develop community alternatives.

The findings from this study suggest that it was not the policy decision to close an institution that resulted in the reluctance and backlash on the part of some families. Rather, it was their exclusion from decisions about the nature of community supports and services that would be delivered that was the source of their rejection of the policy. One parent said that many of these families were concerned that, "community alternatives provide safety, security, stability, and structure when needed." Interviews with some parents indicated that parents' exclusion from the decision-making process may also restrict their own vision and expectations for their sons or daughters. This may lead them to favour institutional care. As one parent said:

> *Parents are expected to play a role but aren't given any power. If parents had the power the attitude would change ... There are "hidden" families out there. They still have a conscience, they still have a commitment to that kid who was theoretically abandoned. We're still living with that. We had to do it. Which experts are we supposed to believe? The ones who told us thirty years ago that this [the institution] was the best thing? Now we're told that it's wrong. We've become schizophrenic. Which experts are right? "Community Living" — the concept is sound if you can make it work. But since the commitment to close institutions, society has changed. People are selfish, life is so complicated. Somehow parents and siblings have to be given the power... You can see the anger growing ... Somehow parents need a sense of being able to take control.*

In the fall of 1988 a temporary moratorium was placed on the downsizing process at Woodlands in order that the government could review the process. The review was in response to a number of concerns which had been voiced, among which were the lack of family involvement in the planning process, the process of resource development, funding, and the quality of community services. The report based on the review recommended that the planning procedures be changed in order to increase family involvement. The report also recommended that General Service Planning be managed by field social workers who were to act as a "fixed point of responsibility" for the individual and family in the planning process.[3]

The research did not determine the extent to which the recommendations from the review were implemented. However, a few parents, who had experience or information concerning the procedures implemented prior to and after the review, felt that neither process gave any real decision-making opportunity to families. One parent, reflecting on the changes that had been made after the review, said:

> *Parents are supposed to have a role in selection of caregivers, but they [the staff of the institution] are coming to the GSP meeting when really the decisions have already been made.*

SUMMARY

Status and recognition for families and friends was most strongly secured when the GSP served as the basis for funding and contracting. The contractual conditions that families specified for service delivery were based on their personal knowledge of an individual. Terms were also based on their knowledge of the other services and resources that would be needed. As well, some families were able to specify a set of conditions for designing services that could meet particular interests and needs of the individual.

Government documents and interviews with government officials indicated that some opportunities had been created for parents to advise in decisions about the community placement of their son or daughter. However, parents were restricted from the decisions concerning selection of service providers and the conditions of their funding. Some parents felt that the tendering procedures thereby restricted the status of the family in significant areas of decision making.

The research found that three reasons were used to justify the restricted status of families in decision making:

- the need to move quickly and efficiently in downsizing the institution conflicts with the extensive involvement of families;

- the government is accountable to the taxpayer and tendering procedures (which have the effect of excluding individuals and families from choosing service providers) secure this accountability;

- some parents are opposed to institutional closure and do not want to make decisions to move their son or daughter to the community.

The research did not test the validity of these justifications or evaluate the procedures for downsizing Woodlands. It did find that the procedures for downsizing Woodlands resulted in the perception by some parents that they had been kept out of the decision-making process. The research also showed that while some parents were opposed to institutional closure, this may have resulted from the exclusion of parents from the decision-making process. It was suggested by some parents that when they had the opportunity to make decisions about community alternatives, their opposition to their son's or daughter's move to the community faded.

Notes

[1] British Columbia, Ministry of Social Services and Housing, *From Institution to Community: Parental Involvement in Community Placement Planning* (Victoria: January, 1987).

[2] *Ibid.*, p. 3.

[3] British Columbia, Ministry of Social Services and Housing, *The Review, Services for Individuals with Mental Handicaps, The Downsizing of Woodlands and Glendale* (Victoria: December 9, 1988).

CHAPTER 7

APPLICABILITY TO OTHER SECTORS

The purpose of this chapter is to consider the applicability of the mechanisms of fixed point service brokerage and individualized funding to other sectors or populations. For the purposes of this examination three populations will be considered — those with physical disabilities, the frail elderly population, and those with a mental or psychiatric disability.

The number of individuals that fall within these three groups is difficult, if not impossible, to determine. The measurement of "disability", "impairment", "frailty" and "mental disorder" is subject to conceptual, diagnostic, and methodological issues and problems. The Health and Activity Limitation Survey estimates that 3.3 million Canadians have some form of disabling condition.[1]

It has been estimated that between 2 and 3 percent of the Canadian population have a major mental disorder[2], and that between 10 and 20 percent of the population will likely present emotional or behaviourial problems to the primary health care system in any given year.[3]

The elderly population in Canada is increasing. It is expected that the population aged sixty-five and over will triple from the 1986 level to 7.5 million by the year 2031. Within this group, rapid growth in the group seventy-five and over is expected, and a tripling of those aged eighty-five and over is anticipated. The likelihood of mentally and physically disabling conditions increases substantially after the age of seventy-five, and it is expected that 20 percent of those over aged eighty-five have some form of dementia or brain disease.[4]

It is estimated that over one million individuals in Canada have some form of physical handicap (including those with a mobility, and/or agility impairment). Various levels of severity of disability within this group are reported.[5]

It is important to note that these are not mutually exclusive groups. Individuals who are elderly may be frail as a result of functional incapacities arising from a physical disability and/or a form of dementia or some other mental disorder. According to the Health and Activity Limitation Survey one third of all disabled persons in Canada are aged sixty-five years or older.[6] Those with a physical handicap may also have a mental impairment or disorder. A recent study estimates that between 11 and 12 percent of people with a physical disability also have a psychiatric disability. It is estimated that only 2 to 3 percent of the general population have a psychiatric disability. The study also indicates that over 70 percent of people with a psychiatric disability report other form(s) of disability.[7]

It is generally agreed that, for a number of reasons, many within these groups are vulnerable with respect to their self-determination, autonomy, and dignity. The extent of their needs makes them especially dependent on others. They may have difficulty in communicating or may be unable to communicate their wishes. They may have to receive services in settings which deny them control over their lives, and which pose risks to their basic rights. And because they may be poor and especially dependent on others, they may be unable to protect themselves from abuse and neglect.[8]

This chapter will examine three factors, based on existing research and literature, that are considered to pose risks to the self-determination, autonomy, and dignity of individuals within these groups. These factors include:

- poverty
- limited access, availability, adequacy, and accountability of community support services
- the legal framework for making decisions when adults are considered legally incompetent or at risk of abuse or neglect.

The following sections will discuss the issues of self-determination, autonomy, and dignity that are raised by these three factors.

The applicability of fixed point service brokerage and individualized funding in addressing these issues will then be examined.

POVERTY

THE ISSUES

Research has found that the vast majority of people with disabilities are poor, as are many individuals in the elderly population.[9] For people with a disability, poverty results from barriers to paid employment, and social assistance programs that do not fully account for the needs that individuals have as a result of a disabling condition. The existence of poverty is central to understanding the risks to self-determination, autonomy, and dignity experienced by individuals in these groups. For example, in research concerning these groups poverty has been associated with:

- a lack of independence and control in individuals' lives;
- an inability to meet basic needs;
- physical and mental ill-health;
- homelessness;
- elder abuse;
- stigmatization which results from the "welfare orientation" of those on social assistance;
- a violation of civil liberties that results from intrusive monitoring by welfare officials, monitoring which is intended to insure continued eligibility for social assistance;
- "double jeopardy" in which individuals with a disability encounter barriers to employment, but have to live on low levels of social assistance designed in part as an incentive to gain employment.[10]

APPLICABILITY

Individualized funding has been proposed as a strategy to alleviate the inequities, discretionary power of financial assistance workers, lack of accountability to individuals, and stigmatization that result from the current income security system. Although there are many proposals for individualized funding, there is basic agreement that individuals require entitlements both to an adequate basic income which reflects the cost of living, and to funding for the purchase of goods and services required as a result of a disabling condition. Individualized funding is expected to promote the dignity of individuals by minimizing requirements for intrusive monitoring, and to increase their opportunity to make decisions about the goods and services that will be purchased to meet their needs.[11]

The impoverishment of many individuals within these groups has resulted in extensive unmet demand for goods and services such as affordable and appropriate housing, technical aids, and home or attendant care. In order to respond to this demand, individualized funding would have to represent more than a "procedural" change in the mechanism for allocation of resources. It may require more than a "re-allocation" of funding from service providers to individuals. Allocation of new dollars may be required as well.

COMMUNITY SUPPORT SERVICES

THE ISSUES

Research indicates that while community support services have expanded in recent years individuals within these groups continue to encounter a number of problems which are found to pose risks to their self-determination, autonomy, and dignity.

For those with mental disabilities some research suggests that a small proportion of individuals are over-resourced in highly specialized services, while the largest proportion receive inadequate or no supports in the community. The research also indicates that for this group the bulk of government funding for supports is allocated to institutional alternatives (between 66 and 92 percent depending on the province), with the remainder allocated to community support services.[12] Research states that housing and crisis intervention are critically needed. The Canadian Mental Health Association cites research that indicates 30 to 40 percent of the homeless population in Canadian cities are people with psychiatric disabilities.[13] As well, community support services have been found to be inadequate, unable to meet demand, discontinuous, and fragmented. They have also been found to emphasize a medical and institutional model to the exclusion of community-based alternatives which are oriented to ongoing support and independence.[14]

Concerning those who are elderly, a recent national consultation on needs of the elderly identified the absence or inadequacy of community support services as a significant problem.[15] The lack of appropriate community support services has been seen as one factor which has led to unnecessary institutionalization of individuals who are elderly, and which prevents their return to community living arrangements.[16] While a number of home care and homemaker services to support the elderly in the community have developed throughout Canada, the distribution of and accessibility to these services varies substantially. Some services are funded under federal-provincial cost-sharing arrangements and in certain provinces municipalities are required to finance a share of the cost. Where municipalities are unable to allocate adequate funding to such services, they may not be able to access federal and provincial dollars.

Where these services are not universally available, as they now are in some provinces, the cost of the service to the consumer has posed an accessibility problem for some individuals. Restrictive criteria that emphasize acute, medical and short-term needs, as distinct from chronic, long-term needs, has also restricted access to services. Substantial inequities in accessibility and availability have been found within and among provinces and territories.[17]

For many individuals with a physical handicap, a number of support services are required for independent living in the community, in particular, attendant care, adequate housing, aids and devices, and transportation. While there is significant unmet demand for these supports, aggregate supply of the supports is not the only issue. Restrictive criteria for access to attendant care, for example, and inflexibility in the hours and location in which attendant care can be provided, have also been found to limit choices for those with a physical handicap. Lack of attendant care has resulted in the exclusion of some individuals from training, education, and employment opportunities.[18]

The delivery of community support services raises two issues which are of common concern to individuals in these groups: (1) accessibility to appropriate services, and (2) accountability to the individual. First, the need for assistance in facilitating access to services, gathering information about available services, and coordinating services for the individual, is identified many times in the research cited. Access to information, individual planning, and coordinating services is central to an effective community support system. In many instances, services are available, but are not accessible or appropriate because of a lack of information or knowledge about how to adapt services to meet individual needs.

Second, the lack of accountability of service providers to the choices of individuals is identified as a significant issue in much of the research cited. The evaluation of the CLS suggested that the issue of accountability is central to securing greater self-determination, autonomy, and dignity for individuals who are in some way vulnerable. Lack of accountability may be due to restrictive criteria established under funding programs, and by service providers. The lack of opportunity for individuals to specify the kinds of staff support they need, their training requirements, and the conditions of their employment have also been identified as barriers to greater accountability.

APPLICABILITY

Individualized funding and fixed point service brokerage appear to have significant potential to address issues of access to support services. Service brokers were effective insofar as they provided needed information, assisted in planning, and had the status to assist individuals in negotiating and arranging service delivery, where they were so requested by the individual.

The effectiveness of fixed point service brokerage in addressing issues of access, availability, and adequacy of support services is likely to depend on the financial mechanisms in place. Based on the CLS evaluation, service brokers appeared to be most effective in resource development when there was a financial incentive or contractual requirement for providers to develop and adapt their services according to the needs and expectations of particular individuals. Service brokers were found to be effective in linking individual planning and resource development when this incentive was in place. Some form of individualized funding would appear to provide the incentive for this pattern of resource development to evolve. This pattern would be quite distinct from the predominant approach in which community services are developed and individuals are required to adapt to the criteria of the program or service provider.

To the extent that individuals are funded according to individual needs, both for basic needs and disability-related needs, issues of restrictive criteria, inappropriate services, and discontinuous services may be addressed. Individualized funding would ensure that the primary criterion for funding and service delivery would be individual need. Direct funding to the individual or contractual status in purchase of service agreements would also be a means for ensuring greater accountability to individuals.

While individualized funding may be an effective mechanism for expressing demand in the market for support services, demand-side mechanisms may not be adequate to ensure an affordable and appropriate supply of some supports, particularly housing. Shelter allowances (in addition to the shelter components of social assistance) is one example of individualized funding in the housing sector. They have been introduced in some provinces to assist the elderly, and in some cases individuals with a disability, in accessing affordable housing. The benefits for the consumer include the choice and portability in the housing market that these mechanisms can potentially facilitate. However, evidence on the effectiveness of shelter allowances in some jurisdictions in Canada (as distinct from the shelter components of social assistance), and in the United States, indicates that supply-side mechanisms are still required to stimulate the supply of affordable housing. The housing market does not automatically respond to shelter allowances with an increased supply of affordable housing.[19]

There are also supply issues to be addressed concerning attendant care and staff support, issues which cannot be fully addressed by service brokerage and individualized funding. One such issue is the availability of adequately trained support staff. A study of individuals with physical handicaps suggests that while the majority of individuals want to maintain greater control over hiring and firing of support staff, a variety of models of staff training may need to be in place. Some individuals want to train attendants on their own; others, because of their needs, require attendants with some medical training; others may not be able to manage independently, but do not require professionally trained support staff.[20] In research on community support services for the elderly, one of the key problems identified was a lack of adequately trained homemakers and home care staff. There has been wide variation in the level of staff training. There has been a tendency in some cases to "over-professionalize" staff. The levels and nature of training were not always found to be a direct reflection of the needs or expectations of the elderly persons who were served.[21]

Implementation of individualized funding mechanisms would shift the emphasis from the development of service providers which employ staff to the development of a labour market which would be capable of responding to the diverse needs of individuals for staff support and attendant care. To ensure that this market attracts adequately skilled, committed, and appropriate support staff, issues of compensation, benefits, and security would require attention. These issues are not simply addressed through the mechanism of individualized funding. Models to encourage adequate and appropriate supply would still need to be developed. These models could include, among others, agencies which make a pool of staff available for contracting by individuals; a loose network of self-employed attendants; associations of attendants acting as independent contractors; or staff hired through consumer or other community-based organizations.

A shift to a system based on individualized funding would likely generate the need for an expansion of support services for individuals' financial management and accounting. This function is now managed by the providers who are funded directly to deliver services. The research cited indicates that a number of options would have to be in place, from individuals managing and administering their support services on their own, to this service being contracted out to an agency. The CLS model of attaching service brokerage to an "autonomous fixed point of response" provides one model: in addition to providing the function of service brokerage, the fixed point can also provide support in accounting and financial tracking of dollars.

THE LEGAL FRAMEWORK FOR MAKING DECISIONS

THE ISSUES

A third factor that poses substantial risks to the self-determination, autonomy, and dignity of individuals is the legal framework for making decisions on behalf of individuals who are vulnerable. Legal structures have been established for granting decision-making power to guardians or substitute decision-makers when individuals are considered incompetent with respect to making property, medical treatment, or personal care decisions, or where they are considered to be the victims of abuse or neglect.

Guardianship legislation in Canada, which provides for substitute decision making by guardians or trustees in the event of a declaration of an individual's incompetence, has been criticized on the basis that it is an "all-or-nothing approach". The powers granted to substitute decision-makers under this legislation can deny individuals control over all aspects of decision making in their lives, even though the areas in which individuals are not able to make decisions are specific and limited.[22] It has been suggested that such powers represent an unnecessary intervention into individuals' lives where more limited or temporary guardianship measures may be sufficient to assist an individual. In this regard such legislation has been considered unable to meet the test of "least restrictive alternative".[23]

Legal and ethical analyses have also suggested that in many cases guardianship, even of a temporary or limited nature, violates the principle of least restrictive alternative. In their analysis, Savage and McKague suggest that the alternative to incompetency declarations provided through partial guardianship may result in greater willingness on the part of the courts to "infringe on the autonomy of individuals" and for judges "to inquire less assiduously into the person's need for a substitute decision-maker".[24]

Similar criticisms have been made of adult protection legislation. This kind of legislation has been enacted in the Maritime provinces and provides powers to remove individuals from situations of abuse or neglect. In some cases, it requires mandatory reporting where there is reasonable evidence that a vulnerable adult (by virtue of incapacity) is a victim of abuse or neglect.[25] Adult protection legislation, with its powers of intervention and mandatory reporting, has been criticized for the lack of safeguards it provides for due process. Concern has been raised that this may be a violation of equality and legal rights under the Canadian Charter of Rights and Freedoms.[26]

Some authors suggest that an emphasis on the need for guardianship or adult protection legislation can misplace the problem of vulnerable individuals in the community. These analyses suggest that the real needs are for adequate community support services, advocacy, service coordination, and decision-making assistance that is not mandated by the courts but is directly accountable to the individual. It is suggested that guardianship and adult protection legislation should be a last resort, and it is implied that the application of powers under this legislation represents the failure of an effective community support system.[27]

There is a distinction made in these analyses between legislative/guardianship approaches to the needs of vulnerable individuals who are considered incapable of making certain decisions, and non-legislative approaches. The latter kind of approach is seen as an alternative to guardianship and as a check on such a system. Non-legislative approaches are often assumed to require a system of advocacy for individuals. In this vein, the Ontario "Advisory Committee on Substitute Decision Making for Mentally Incapable Persons" recommended that a Substitute Decisions Act not come into force in Ontario until a system of advocacy services was implemented.[28] The purpose of making advocates available would be to guard against unnecessary or unwarranted use of the powers under the legislation. As recommended by the Committee, the objectives of advocacy services should be:

- to promote respect for the rights, freedoms and dignity of the persons they serve, both individually and collectively;

- to ensure that their clients' legal and human rights are recognized and protected;
- to assist their clients to receive the health care and social services to which they are entitled and which they wish to receive;
- to enhance the autonomy of their clients by advocating on their behalf, both individually and collectively;
- to assist their clients in leading lives that are as independent as possible, and in the least restrictive environment possible;
- to help protect persons who are mentally disadvantaged from financial, physical and psychological abuse;
- to fully explain the implications of and provide advice with respect to guardianship and conservatorship under the Substitute Decisions Act (or the current legislation it is intended to replace).[29]

In order to examine the mandate and options for advocacy services in Ontario proposed by the Committee on Substitute Decision Making, another Review Committee was established by the Ontario Attorney General. That committee adopted the same basic objectives identified above as the foundation for advocacy services and recommended the establishment of a provincial Advocacy Commission. The Commission would be responsible for regional offices which would hire advocacy coordinators and develop appropriate local programs. Advocates would be trained and certified in accordance with standards established by the Commission.[30]

Savage and McKague suggest that the alternative to the legislative approach is the provision of "decision-making assistance" possibly in the form of advocacy services or "adult protective service workers" (APSWs). They view advocates and APSWs as options for delivering decision-making assistance, but do not equate these options with the function or need for decision-making assistance. That is, they do not suggest that the need is for advocacy, but rather for decision-making assistance. They suggest that any individuals, programs, or agencies which deliver decision-making assistance should be independent of direct service providers in order to avoid conflicts of interest. Their conceptual distinction between decision-making assistance and advocacy allows for an examination of the effectiveness of formalized advocacy services as one delivery option in addressing the need for decision-making assistance.

APPLICABILITY

The applicability of fixed point service brokerage to the issues raised by the legal framework of guardianship and adult protection legislation resides in its potential to be an option for delivering decision-making assistance. The question is whether service brokerage is able to meet the needs for decision-making assistance for which advocacy services have been recommended. The analysis in this study suggests that fixed point service brokerage can meet these needs.

Based on the research cited throughout this chapter, the kinds of decision-making assistance required includes not only advocacy but also other forms of assistance which brokers have been effective in providing: information, service coordination, individual planning, assistance in accessing service providers, and facilitation of resource development. As well, the objectives for advocacy services identified above suggest principles which are adhered to by service brokers (promotion of human rights and freedoms, and autonomy). The objectives also identify functions which brokers have or could carry out, functions that are distinct from the advocacy that may nonetheless be essential.

There are two benefits to using fixed point service brokerage as one of the delivery mechanisms for the decision-making assistance required to protect individuals from the risks to self-determination, autonomy, and dignity posed by the legal framework. First, it does not remove the function of advocacy from family, friends, and other volunteers, that might result if an advocacy system were put in place that required training, certification, and appointment of advocates.

Second, it does not require the establishment of an administrative system in addition to a system for service coordination, now widely recognized as a critical need for many individuals and families. Further, extensive new funding would need to be allocated to implement an option for formalized advocacy services. Fixed point service brokerage might be implemented through a re-allocation of resources. It is an alternative to the delivery mechanisms that currently exist for case management and service coordination that are based in funding agencies or direct service providers. A more effective service coordination function to meet unmet needs would likely require, however, more than a re-allocation of funding to a fixed point service brokerage system. In order to establish a system on a provincial basis, substantial start-up and ongoing funding would probably be required.

The applicability of fixed point service brokerage lies then in its ability to respond to the needs for service coordination that arise from a complex community support service system. Applicability also lies in its potential, through the provision of decision-making assistance, to limit the application of powers of substitute decision making under guardianship and adult protection legislation.

SUMMARY

This chapter has briefly examined the applicability of fixed point service brokerage and individualized funding to issues of self-determination, autonomy, and dignity for individuals with a psychiatric or mental disability, those with a physical handicap, and those who are frail and elderly. The analysis suggests that factors which pose risks to self-determination, autonomy, and dignity of individuals in these groups include: poverty; the community support service system (in terms of availability, accessibility, adequacy, and accountability); and the legal framework for making decisions when individuals are considered to be incompetent to make certain decisions or who are considered to be victims of abuse or neglect.

It is suggested that individualized funding could play an important role in addressing the issues raised by these factors insofar as it provides mechanisms for accountability of service providers to individuals. It establishes that individual need is the principle criterion of funding and service delivery, and it accounts for entitlements to funding for both basic needs and disability-related costs. However, while individualized funding may encourage the supply of services to respond more effectively to demand, it does not address the supply issues raised by a lack of goods and services like affordable housing and appropriately trained support staff. These are both critical issues for individuals in these groups.

Fixed point service brokerage is applicable to addressing the needs identified for service coordination, information, and planning assistance. Its effectiveness in providing this assistance depends to some extent on the funding mechanism in place. Service brokers are likely to be more effective where individualized funding is implemented because it provides incentives and requirements for service providers to adapt to the particular needs of individuals, and to recognize the role of the broker.

Fixed point service brokerage may be one option for delivering the decision-making assistance which seems to be required in order to limit the unnecessary use of court-appointed powers for substitute decision making. This intervention, through guardianship legislation or adult protection legislation, has been found to pose risks to self-determination, autonomy, and dignity. Underlying reasons which precipitate such interventions include lack of or inadequate access to community support services, and lack of assistance in making decisions. Fixed point service brokerage, autonomous from the service delivery system, has been found to be effective in providing the kinds of decision-making assistance which have been suggested as an alternative to court-appointed, substitute decision makers.

Fixed point service brokerage does not replace the need for advocacy, as was demonstrated in this research. However, its systematic implementation may obviate the need for extensive development of formalized advocacy systems that have sometimes been seen as the only alternative for limiting unwarranted use of legislated powers of substitute decision making.

Notes

[1] Statistics Canada, The Health and Activity Limitation Survey, *Highlights: Disabled Persons in Canada* (Ottawa: March 1990).

[2] See R.C. Bland "Long Term Mental Illness in Canada: An Epidemiological Perspective on Schizophrenia and Affective Disorders" *Canadian Journal of Psychiatry* vol. 29 (1984) pp. 242-246; Paula Goering, William Lancee and Jeanette Cochrane, *Validation of a Measure of Psychiatric Disability in a Community Sample* (Ottawa: Statistics Canada, January, 1989).

[3] See Robert Graham, *Building Community Support For People: A Plan For Mental Health in Ontario*, Report of the Provincial Community Mental Health Committee (Toronto: Ministry of Health, July 1988).

[4] See Health and Welfare Canada, *Charting Canada's Future: A Report of the Demographic Review* (Ottawa: 1989); Statistics Canada, *The Seniors' Boom* (Ottawa: 1986).

[5] See Statistics Canada, Health and Activity Limitation Survey.

[6] *Ibid.*

[7] See Paula Goering, William Lancee and Jeanette Cochrane, *Validation of a Measure of Psychiatric Disability in a Community Sample* (Ottawa: Statistics Canada, January 1989).

[8] For a discussion of vulnerability in these terms see Ontario Ministry of the Attorney General, *You've Got a Friend: A Review of Advocacy in Ontario* (Toronto: 1987).

[9] See Sherri Torjman, *Income Insecurity: The Disability Income System in Canada* (Toronto: The G. Allan Roeher Institute, 1988); Secretary of State, *Profile of Disabled Persons in Canada* (Ottawa: 1986).

[10] See Canadian Mental Health Association, *A Framework for Support for People With Severe Mental Disabilities* (Toronto: December 1984); Centre for Research and Education in Human Services, *Independence and Control: Today's Dream, Tomorrow's Reality* (Toronto: Ontario Ministry of Community and Social Services, 1988); Canadian Organization of Provincial Organizations of the Handicapped, *COPOH'S Preliminary Position on Fiscal Arrangements Affecting Disabled Canadians* (Winnipeg: November 1987); Health and Welfare Canada, *Abuse and Neglect of the Elderly* (Ottawa: 1986); Joseph Hornick, Lynn McDonald, Gerald Robertson, and Jean Wallace, *A Review of the Social and Legal Issues Concerning Elder Abuse* (Calgary: Canadian Research Institute for Law and the Family, October 1988); and, National Council of Welfare, *Welfare in Canada: The Tangled Safety Net* (Ottawa: November 1987).

[11] See Sherri Torjman, *Income Insecurity: The Disability Income System in Canada*. Many organizations speaking to the needs of those with physical handicaps have expressed the view that a form of individualized funding or "independent living allowance" is required if independent living in the community is to be attained. There have also been recommendations that this system should be implemented with a form of service brokerage. See Attendant Care Action Coalition, *Options for Independent Living Assistance* (Toronto: 1986); Centre for Research and Education in Human Services, *Independence and Control: Today's Dream, Tomorrow's Reality*; Coalition of Provincial Organizations of the Handicapped, *COPOH'S Preliminary Position on Fiscal Arrangements Affecting*

Disabled Canadians; Ontario Advisory Council for Disabled Persons, *Independent Living: The Time is Now* (Toronto: March 1988).

[12] Bonnie Pape and Kathryn Church, *Community Reinvestment* (Toronto: Canadian Mental Health Association, 1987).

[13] *Ibid.*

[14] See, for example, Reva Gerstein, *The Final Report of the Mayor's Action Task Force on Discharged Psychiatric Patients* (Toronto: City of Toronto, 1984); Robert Graham, *Building Community Support for People*, Report of the Provincial Community Mental Health Committee (Toronto: Ministry of Health, 1988); Task Force on Mental Health Services for Persons with Disabilities, *Access to Mental Health* (Toronto: Metropolitan Toronto District Health Council, July 1989); John Trainor and Kathryn Church, *A Framework for Support for People with Severe Mental Disabilities* (Toronto: Canadian Mental Health Association, December 1984).

[15] National Advisory Council on Aging, *Understanding Seniors' Independence, Report No. 1: The barriers and suggestions for action* (Ottawa: May 1989).

[16] Price Waterhouse/Medicus, *Direct Nursing Requirements of Extended Care Residents in Homes for the Aged and Nursing Homes in Ontario,* volumes 1 and 2 (Toronto: Office of Senior Citizens' Affairs, March 1988).

[17] See William F. Forbes, Jennifer A. Jackson, and Arthur S. Kraus, *Institutionalization of the Elderly in Canada* (Toronto: Butterworths, 1987); National Advisory Council on Aging, *Toward a Community Support Policy For Canadians* (Ottawa: January 1986).

[18] See Centre for Research and Education in Human Services, *Independence and Control: Today's Dream, Tomorrow's Reality* (Toronto: Ontario Ministry of Community and Social Services, 1988); Coalition of Provincial Organizations of the Handicapped, *COPOH'S Preliminary Position on Fiscal Arrangements Affecting Disabled Canadians.*

[19] David Hulchanski, *Shelter Allowances and Canadian Housing Policy* (Toronto: Centre for Urban and Community Studies, University of Toronto, 1983).

[20] Centre for Research and Education in Human Services, *Independence and Control: Today's Dream, Tomorrow's Reality.*

[21] See Canadian Council on Homemaker Services, *Visiting Homemakers Services in Canada: Survey, 1982* (Toronto: 1982); C. Matthews and J. Stryckman, *Adapting to an Aging Population Through Education* (Ottawa: National Advisory Council on Aging, 1988); National Advisory Council on Aging, *Understanding Seniors' Independence* (Ottawa: May 1989).

[22] The *Dependent Adults Act* (1980) in Alberta is distinguished from other guardianship legislation in Canada. This legislation grants to the public guardian only those powers necessary to assist or make decisions in those particular areas of decision making where a ruling of incompetency has been made.

[23] See Joseph Hornick et al., *A Review of the Social and Legal Issues Concerning Elder Abuse;* G. B. Robertson, *Mental Disability and the Law in Canada* (Toronto: Carswell, 1987); H. Savage and C. McKague, *Mental Health Law in Canada* (Toronto: Butterworths, 1987).

[24] H. Savage and C. McKague, *Mental Health Law in Canada.* pp. 194-196.

[25] Joseph Hornick et al. indicate that provisions for mandatory reporting by an individuals' physician, physician-patient confidentiality notwithstanding, are also contained in the Ontario *Nursing Homes Act* (1980). The authors suggest, based on other research, that such provisions may discourage the victim of elder abuse from seeking medical assistance (pp. 101-102).

[26] See R.M. Gordon, S.M. Verdun-Jones, and D.J. McDougall, "The Implications of the Canadian Charter of Rights and Freedoms for the Law Relating to Guardianship and Trusteeship," *International Journal of Law and Psychiatry*, vol. 10: pp. 21-34; Joseph Hornick et al., *A Review of the Social and Legal Issues Concerning Elder Abuse.*

[27] Stephen Fram, *Final Report of the Advisory Committee on Substitute Decision-Making for Mentally Incapable Persons* (Toronto: Ontario Ministry of Health, 1987); Ontario Ministry of the Attorney General, *You've Got a Friend: A Review of Advocacy in Ontario.*

[28] Stephen Fram, *Final Report of the Advisory Committee on Substitute Decision-Making for Mentally Incapable Persons.* p. 86.

[29] Stephen Fram, *Final Report of the Advisory Committee on Substitute Decision-Making for Mentally Incapable Persons*, pp. 81-82.

[30] Ontario Ministry of the Attorney General, *You've Got a Friend.*

CHAPTER 8

CONCLUSIONS

The primary purpose in undertaking this study was to assess the impact of service brokerage and individualized funding on achieving the goal of self-determination, autonomy, and dignity for individuals with a mental handicap. In evaluating the impact of these mechanisms, some comparison to more conventional mechanisms for delivering financial and planning resources could not be avoided. For the purposes of the analysis, these conventional mechanisms were termed "service funding" and "government- or service provider-based planning".

Tables 1 & 2 provide a framework for comparing these distinct planning and funding mechanisms (see following pages). The framework identifies the kinds of decisions which individuals and families stated they wanted to be able to make, and the procedures associated with each mechanism for making these decisions. The framework is not meant to be either conclusive or definitive. It does provide a basis for organizing the conclusions to this study, presented below in summary fashion.

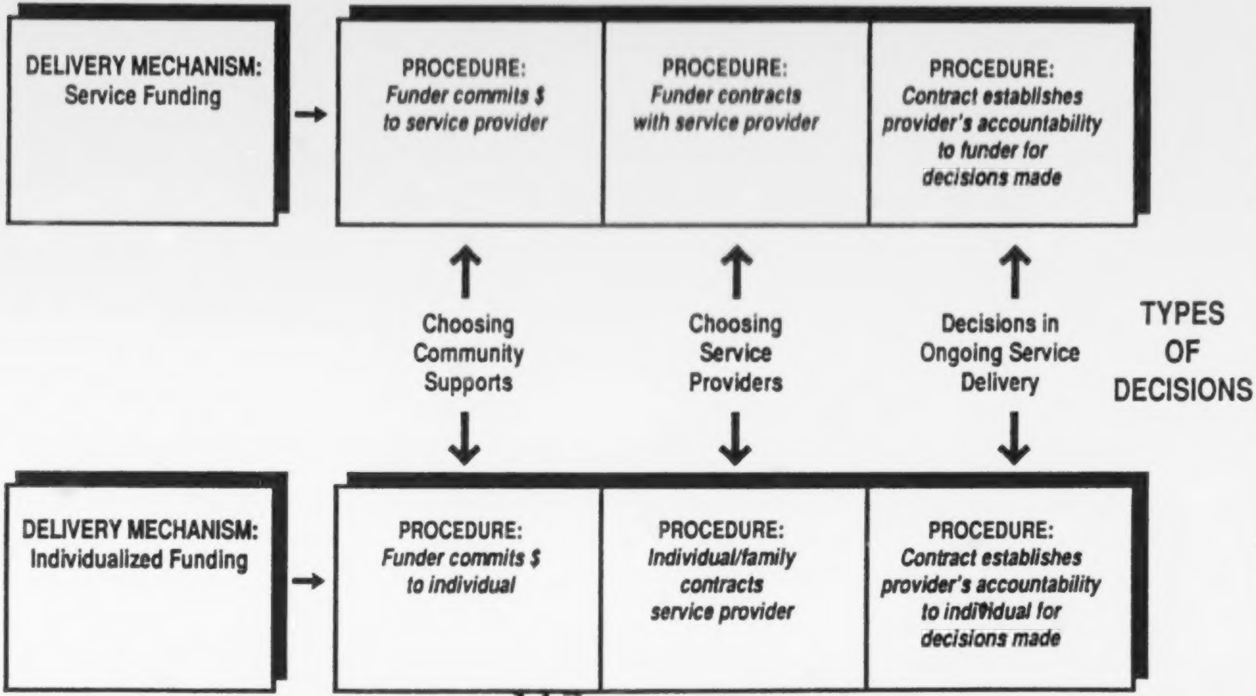
CONVENTIONAL PLANNING AND FINANCIAL MECHANISMS POSE LIMITATIONS TO SELF-DETERMINATION, AUTONOMY AND DIGNITY

This study suggests that, from the perspective of individuals and families, there are serious limitations in the conventional delivery

Table 1
The Delivery of Planning Resources
Mechanisms, Decisions and Procedures

TYPES OF DECISIONS	Choosing Community Supports	Choosing Service Providers	Decisions in Ongoing Service Delivery
DELIVERY MECHANISM: Government or Provider-based Planning	**PROCEDURE:** *Individual plans developed by funder/service provider (Needs Assessment, IPP, etc.)*	**PROCEDURE:** *Providers chosen through tendering or referral managed by government*	**PROCEDURE:** *Funder/service-provider guides decision-making process through case review, IPPs, etc.*
DELIVERY MECHANISM: Autonomous Fixed-point and Service Brokerage	**PROCEDURE:** *Individual plans developed by broker (General Service Plan), with direction by individual/family*	**PROCEDURE:** *Providers chosen by individuals and families, based on terms of GSP, and options identified by broker*	**PROCEDURE:** *Broker facilitates decision making where requested by individual, family or service provider*

Table 2
The Delivery of Financial Resources
Mechanisms, Decisions and Procedures


DELIVERY MECHANISM: Service Funding
PROCEDURE: Funder commits $ to service provider
PROCEDURE: Funder contracts with service provider
PROCEDURE: Contract establishes provider's accountability to funder for decisions made
Choosing Community Supports
Choosing Service Providers
Decisions in Ongoing Service Delivery
TYPES OF DECISIONS
DELIVERY MECHANISM: Individualized Funding
PROCEDURE: Funder commits $ to individual
PROCEDURE: Individual/family contracts service provider
PROCEDURE: Contract establishes provider's accountability to individual for decisions made

mechanisms for achieving the goal of individual self-determination, autonomy, and dignity. For those interviewed in this study these mechanisms often withheld from individuals, or their families who spoke on their behalf, the status to make basic personal decisions. These decisions were concerned with where individuals would live; with whom they would live; the people who would enter their home; the individual programs that would be delivered to them; the ways in which their needs for support would be defined; the service providers who would be contracted; and the overall direction of their lives.

The basic flaw in these mechanisms appears to be the lack of any structural accountability to the individual or their representatives for decisions that are made. The service funding mechanism is designed to fund the costs of service providers in delivering services. Funding is tied to the service provider and the manner in which they choose to deliver services. The service funding mechanism provides status only to the funding agency and the service provider in purchase of service agreements. For this reason, it appears that service funding may be able to produce a "supply" of services, but may be less effective in responding to the diverse "demand" for services. For those interviewed in this study, this funding mechanisms has resulted in inappropriate and inadequate purchase of services, lack of flexibility in funding, lack of access to financial resources according to individual need, and lack of portability in the service system.

Many who were interviewed felt that social workers employed by the government used restrictive eligibility criteria in arranging access to services and funding. The planning assistance they provided seemed thereby circumscribed, and their accountability to the funding agency, rather than to the individual, seemed thereby ensured. With service providers contractually accountable only to the funding agency there appeared to be few, if any, measures for ensuring accountability to the individual in the decisions they made.

Nor did these mechanisms secure recognition and status for close family and friends in decision making. Many of the individuals included in this study were not able to speak for themselves and required the support of others who were able to advocate for them. Often this role fell to close family members. However, these family members felt they had often been excluded from access to resources, service providers, the service setting, and the decisions made.

The exclusion of families from the decision-making process through the conventional financial and planning mechanisms may have both legal and social ramifications.

First, there may be no strict legal requirement to include families in decision making. However, where their participation is neither rejected by an individual nor demonstrably threatening to the individual's well-being, there does not appear to be legal or ethical justification for excluding them. Further, to exclude them seems to go against established practices in other areas, like medical decision making, which are concerned with decisions that affect the personal autonomy of individuals who may not be declared legally incompetent, but who require assistance in making decisions.

Second, systematic exclusion from decision making may hinder families and friends from developing a "vision" and expectations for community life. This is one reason why some parents are reluctant to see their son or daughter move from an institution to the community. When they had the the opportunity to consider alternatives and make decisions, they supported and strongly advocated for their son's or daughter's move to the community. As one parent said: "If parents had the power the attitude would change. There are 'hidden' families out there."

SERVICE BROKERAGE AND INDIVIDUALIZED FUNDING INCREASE SELF-DETERMINATION, AUTONOMY AND DIGNITY

Service brokerage and individualized funding have been partially implemented for the majority of individuals served by the Community Living Society, and fully implemented in a few instances. There are five factors associated with these mechanisms which appear to substantially increase the self-determination, autonomy, and dignity of individuals, when this goal is measured by the extent of individual decision-making opportunity. These five factors include: (1) the autonomy of fixed point service brokerage; (2) the allocation of funding according to individual need; (3) the contractual status provided to individuals; (4) the linkage between individual planning and resource development; and (5) the recognition provided to close family and friends in decision making.

AUTONOMY OF FIXED POINT SERVICE BROKERAGE

Fixed point service brokerage was designed to provide planning assistance and information, autonomous from the funding agencies and service providers with whom individuals and families have to negotiate. This has been provided by the CLS in some cases. Where fully autonomous, service brokers have assisted in identifying needs and requirements for support and costed these requirements. Service brokers have also identified potential providers, facilitated resource development, and assisted in the implementation and monitoring of service contracts based on the individual's General Service Plan (GSP). The broker's autonomy, ensured where individualized funding was in place, was an assurance that the plan would be designed in collaboration with the individual and his or her family, and implemented only subject to their approval.

From the perspective and experience of families, the autonomy of service brokers increased their effectiveness. When they were not entirely constrained by the criteria for programs and services established under service funding, brokers were able to translate individuals' hopes and expectations into realistic plans for living in the community. Further, the autonomy of the broker seemed to ensure more effective assistance in the negotiations for funding and in the contracting of service providers than the planning assistance of the social worker.

The autonomy of service brokers was also found to be an important factor in their ability to mediate conflicts between individuals, providers, and families, and in their ability to facilitate resource development.

ALLOCATION OF FUNDING ACCORDING TO INDIVIDUAL NEED

With regard to funding, individuals and families indicated that decision-making opportunity was best secured when the primary criterion for allocating funds was that of individual need. In their experience, they had found that other criteria were often used with the consequence that individuals were not able to access appropriate supports and services. Individualized funding is based on the principle that individual need should be the primary criterion. The GSP has served in some cases as a means for ensuring that funding allocations were made on this basis. However, in the case of most individuals served by the CLS, the GSP has been used to individually cost services and supports, while funding allocations continue to be based on ministry-selected "program models", and the costs incurred by service providers. Most GSPs have, then, been individually costed, while in a few cases they have been individually funded.

This distinction between individually costed GSPs and individually funded GSPs is crucial for the decision-making opportunities afforded to individuals. It was only when funds were actually allocated to an individual's GSP, that he or she had status in decision making. In these cases the funding followed individuals, the supports were delivered where individuals were or where they chose to be, and not necessarily where service providers chose to deliver services.

CONTRACTUAL STATUS PROVIDED TO INDIVIDUALS

"Contractual status", provided through individualized funding (funding allocated to an individual's GSP), is a third factor that has increased decision-making opportunities. For many of those who were interviewed, the decisions about supports and services to be received were always negotiated ones. The experience of individuals and families was that they have often been excluded from these negotiations. Where they have not been involved, negotiations have concluded in decisions with which individuals and families have had to live, but decisions which are often not of their making.

Contractual status meant that individuals and their representatives had a position in negotiations, and had the opportunity to determine the conditions for agreements with service providers. The research suggests that individuals and families wanted to be able to specify, contractually, the nature of goods and services required; the conditions of access to the service setting by family, friends, and others; the procedures by which decisions would be made in ongoing service delivery; and the procedures to be used for quality assurance and monitoring.

By allocating funding to individuals and providing them with contractual status to make decisions, individualized funding may also be a means for increasing portability in the community support system. Lack of portability is recognized as a serious problem by consumers, service providers, and government.

Contractual status for the individual has been implemented in only a few instances. Through the 1978 agreement between the CLS and the B.C. government, contractual status was to be provided to all individuals served by the CLS. The historical analysis provided in this study clarified some of the reasons why this status was never fully implemented.

First, the GSP was to be the basis of funding and contractual arrangements. In fact, dollars were negotiated on behalf of GSPs but never, in large part, allocated to the GSP. Funding continued to be allocated to the service provider.

Second, without funding allocated to the individual, the IPP lost its relevance as the basis of a contract. The IPP was initially designed to be prepared by the individual with the assistance of the broker. Its purpose was to provide direction to the service provider, to lay out the basic conditions of funding, and to be a document that had an autonomy from the service system.

In a system without contractual status for individuals, IPPs are prepared by the service provider. From the perspective of many of those who were interviewed, IPPs do not constitute a mechanism for ensuring accountability of the service provider to the individual. Rather, they are a means to provide direction to the individual, to identify the objectives that individuals will seek to achieve with the assistance of the service provider and to specify the criteria that will be used to measure individual progression towards achievement of objectives.

LINKAGE PROVIDED BETWEEN INDIVIDUAL PLANNING AND RESOURCE DEVELOPMENT

A fourth factor that increased opportunities to make decisions was the linkage, facilitated by service brokerage and individualized funding, between individual planning and resource development. By tying the development of residential or vocational resources more directly to the process of individual planning, greater opportunity to influence the nature of these supports was provided.

RECOGNITION OF CLOSE FAMILY AND FRIENDS

A fifth factor that increased individual decision-making opportunity was the emphasis placed by service brokers on the personal knowledge of close family and friends. Where individuals could not fully communicate their strengths, goals, and interests, or advocate for themselves, brokers were able to provide this opportunity to close family and friends. To the extent that family and friends were able to articulate and advocate for individuals, this was one means for individuals to have greater control in the decision-making process. Families were also able to play a role in specifying contractual conditions for service delivery through individualized funding.

EFFECTIVENESS OF SERVICE BROKERAGE DEPENDS ON FUNDING MECHANISM

Service brokerage seemed most effective, according to individuals and families, when brokers were available to assist in defining needs for support, identifying alternatives, providing assistance in negotiations with the funding agency and potential service providers, and facilitating resource development.

However, the ability of the broker to play these roles was fully secured only when individualized funding or contractual status for the individual was in place. Contractual status for the individual meant that the broker was recognized, both by the funding agency and the service provider, as having a role to play as the individual's agent. When there was no contractual status for the individual, service providers were less willing to acknowledge the broker's role. This has proven to be one of the major systemic blockages to the effective implementation of service brokerage since the late 1970s: brokers have no acknowledged role in a system in which the individuals, to whom they act as agents, have no contractual power.

WIDE VARIATION IN ACCESS TO SERVICE BROKERAGE

There were significant variations in access to the planning resources delivered through service brokerage both in general service planning and in ongoing service delivery.

With respect to access to a broker in general service planning, the variation was due in large part to the predominance of service funding mechanisms. Under these mechanisms a diluted form of general service planning often began only after funding commitments were made to the CLS as the residential or vocational service provider. Access to a broker to assist more vigorously in general service planning was fully assured only where individualized funding was in place and where brokers were specifically contracted to carry out the planning function.

Factors affecting access to a broker, in addition to the predominance of service funding, included the availability of individualized funding, the tendering procedures for closing Woodlands, the levels of funding for service brokerage, and the demands of those who were able to strongly advocate for an individual. These factors conspired to restrict fair and equitable access to a general service planning process that was a means for individuals and families to consider options and make decisions about supports and services to be used.

Variation in access to service brokers was also clearly evident in ongoing service delivery. This resulted in part from factors internal to the CLS and was related to the design and implementation of service brokerage.

First, the CLS has tended to discourage the use of formal individual planning methods for ongoing service delivery. This was based on a belief that formalized planning could "institutionalize" service delivery, and impose services on individuals rather than to respond to their particular goals, strengths, and needs. However, this de-emphasis on formal planning procedures has opened up a kind of "planning vacuum" for some residential and vocational staff who provide support to individuals. Some CLS support staff suggested that there was a tendency in some cases for the planning and decision-making process to become so informal that it was almost non-existent. They suggested that this vacuum had undermined both accountability to certain individuals, and the quality of services they received.

Brokers have not been as effective as they might have been in identifying options for managing planning and decision making in ongoing service delivery, and in ensuring that support staff are capable of carrying out the options preferred by individuals and families. If individuals and families are to make decisions about the kinds of ongoing planning procedures that will be used, and are to specify these contractually under individualized funding, then these options need much greater clarity. Without a sense of what options are available — whether they be IPPs, twenty-four-hour plans, or more informal methods — individuals and families are not in a position to specify and negotiate the terms of this process with service providers.

Second, the CLS has not been fully effective in designing procedures for activating service brokerage when it is legitimately required in ongoing service delivery. The reluctance to implement such procedures has been due to a desire to ensure that brokers do not become "interventionist", but respond to the requests of individuals and families. For this approach to be effective, individuals or families must be able to act as advocates. However, most individuals served by the CLS are not able to advocate for themselves, nor do they have family or friends able to advocate for them. Therefore, the capacity to activate service brokers by means other than paid support staff is possible only for a minority of individuals. While paid support staff have played an effective role in activating brokerage in most cases, this has not been an adequate mechanism where the quality of service by support staff is itself at issue.

Recently, and during the latter period of this research, the CLS implemented periodic reviews to enable service brokers to make some contact on a regular basis with all the individuals for whom they brokered. The effectiveness of these procedures in addressing the problem of activating brokerage when needed was not considered in this study. It can be anticipated that individualized design of ongoing reviews by service brokers may be required. That is, service brokers may need to give close attention in general service planning to the needs of particular individuals for advocacy and monitoring supports, and the kinds of ongoing reviews that will be required. Where monitoring and advocacy supports cannot be put in place in the short term, service brokers may need to provide more intensive reviews.

SUPPORT STAFF CRITICAL TO ENSURING ACCOUNTABILITY TO INDIVIDUALS

Support staff indicated that their daily contact with an individual placed them in a unique position to facilitate accountability to the individual. However, the multiple lines of accountability that result from service brokerage and individualized funding make this a difficult task. Where support staff are employed by a service provider, there are three lines of accountability: (1) the individual and the individual's family; (2) the support staff's employer, the service provider; and (3) the service broker who may carry different perceptions of the goals and interests of the individual than the support staff.

In order to manage these various lines of accountability, and ultimately to ensure accountability to the individual, support staff have indicated that it takes more than contractual requirements or their personal commitment. Accountability to the individual also requires increased levels of compensation; staff development which focuses on concrete strategies for increasing accountability to the individual; and a recognition of the pivotal role of front-line support staff in managing accountabilities.

FAMILY AND FRIENDS CRITICAL TO THE EFFECTIVENESS OF SERVICE BROKERAGE

The research suggests that for service brokerage and individualized funding to be effective in creating decision-making opportunities, individuals, or families and friends on their behalf, must be able to carry out certain functions. These functions include advocacy, negotiation for funding and services, and activation of brokerage as it is needed in ongoing service delivery.

However, very few of the individuals who are served by the CLS are able to carry out these functions themselves, and the majority are without family and friends able to carry out these functions for them. If individualized funding and autonomous service brokerage were to be implemented on a large scale, serious attention would have to be given to this fact. Without close family, friends, or advocates, the conditions for funding and service delivery would only be determined by the funding agency, the service provider, or broker. The broker may be in some position to specify these conditions, although this could lead to creating an advocacy role for the broker that would undermine his or her ability to facilitate negotiations and resource development.

The fact that the majority of individuals brokered for by the CLS do not have close family and friends able to effectively advocate and negotiate for them presents a real constraint on the effectiveness of service brokerage and individualized funding in achieving the goals of self-determination and autonomy which the organization espouses. Because of this, brokers, in many instances, have had to make their own assessments of needs and goals based on their sometimes scant knowledge of the individual and on perceptions provided by other professionals. As indicated above, greater attention to needs for advocacy, monitoring, and quality assurance may be required in the general service planning process.

The problem of a lack of close family and friends in the lives of a number of individuals needs to be understood in a historical context. Many of the individuals that the CLS supports have lived in institutions for long periods of time, sometimes more than thirty years. They, more than others, lack close family relationships. With institutions now closing and with a growing emphasis emerging on the rights of individuals with a handicap to participate as full citizens in society, the number of individuals without close family and friends may well be substantially reduced in the future.

SERVICE BROKERAGE AND INDIVIDUALIZED FUNDING — A MEANS TO ARTICULATE "CONSUMER DEMAND"

The findings from this study suggest that service brokerage and individualized funding have been effective in assisting individuals and families to express their "demand" for particular supports and services in the community. In the experience of individuals and families, they were able to articulate their demand for supports and services as a result of the GSP process, the allocation of funding to the GSP, the status to determine contractual conditions for service delivery, and through the negotiating process with the funding agency and service providers.

However, this should not lead to the conclusion that fixed point service brokerage and individualized funding can address all the issues and problems within the community service system; or that all of the emphasis should now be put on the "demand-side" of the service system. The historical analysis provided in Appendix E suggests that the lack of adequate supply of some supports in the community was one of the factors that led the organization, in 1980, to begin delivering residential and vocational services. The lack of an adequate supply of trained support staff and affordable housing was one factor undermining the effectiveness of service brokerage at that time. Through the 1980s the CLS and other community service agencies have developed the expertise to support individuals in the community. This expertise will continue to be required in order to develop an adequate supply of support staff, adequate and accessible housing, property and financial management services, and appropriate vocational, training, and employment supports.

Nonetheless, this study does suggest that the emphasis in British Columbia in the 1980s was on managing the *supply* of supports and services. According to those interviewed, the funders and service providers have not been effective in responding to the *demands* of the consumers, or in tying the development of resources more closely to demand. This has resulted in individuals bearing significant costs in terms of their self-determination, autonomy, and dignity. While service brokerage and individualized funding may not be able to address all the supply issues, they do introduce into the community service system a means for organizing and articulating consumer demand, and linking this demand to resource development.

SERVICE BROKERAGE AND INDIVIDUALIZED FUNDING APPLY TO OTHER SECTORS

This study has also considered the applicability of autonomous service brokerage and individualized funding to other sectors including people with a physical disability, people with a psychiatric disability, and people who are frail and elderly.

The analysis identified three factors which affect the self-determination, autonomy, and dignity of individuals within these groups. These factors include poverty; community support services (in terms of accessibility, availability, adequacy, and accountability); and the legal framework for making decisions when individuals are deemed incompetent to make certain decisions, or are considered to be victims of abuse or neglect.

Service brokerage could serve as a possible mechanism for providing the information, service coordination, individual planning, and assistance in accessing services that have been identified as critical needs for individuals in each of these groups. As well, because of its potential to meet these needs, it may also serve as a mechanism to deliver the decision-making assistance individuals require to limit the use of court-appointed powers of substitute decision making where individuals are considered incapacitated or vulnerable. The use of service brokerage might be a supplement to the need for advocacy supports which have been recommended as one option for decision-making assistance. In this capacity it could help to keep the size of a formal advocacy system within feasible and desirable limits.

The applicability of individualized funding to these groups appears to lie in its emphasis on individual need as the principle criterion for funding allocations. As well, individualized funding could address issues such as accountability to individuals and inflexible and discontinuous services which have been raised in relation to these groups. However, individualized funding would probably not, on its own, be able to trigger an adequate supply of essential goods and services such as affordable housing and appropriately trained support staff and attendant care.

PLANNING AND FUNDING MECHANISMS REFLECT POLICY CHOICES OF GOVERNMENT

This research suggests that governments have a policy choice to make concerning the mechanisms that will be used to deliver financial and planning resources. That this choice has not been clearly or consistently made is evident in the history of the implementation of service brokerage and individualized funding in British Columbia. The consequence has been that two contradictory sets of mechanisms are now in place. This has resulted in inequities in access to planning assistance, to financial resources which are allocated according to individual need, and to contractual status in decision making.

On what basis is a policy choice made about the planning and funding mechanisms to be used? This study suggests that the principles of self-determination, autonomy, and dignity are valid principles to guide such a choice.

On what grounds is it justifiable to use these principles to guide the choice of mechanisms for delivering financial and planning resources? This study suggests two grounds.

First, the aims of self-determination, autonomy, and dignity have been used historically as a basis for critique of institutional care and for advocating for community-based services. Accordingly, policies to close institutions in British Columbia and in other provinces are now being implemented. A principle used in part to justify a policy initiative like deinstitutionalization cannot reasonably be disregarded when it comes to the choice and design of the financial and planning mechanisms for implementation of the policy.

Second, and possibly most important, the choice of planning and financial mechanisms has been found to have fundamental implications for whether self-determination, autonomy, and dignity are achieved for individuals with a mental handicap. Self-determination, autonomy, and dignity are not only aims of social policy, or important societal values. They are principles with profound legal and ethical implications. To systematically deny the realization of these principles in a community service system that is created through policy choices, and to make this denial effective for a certain group of people, is a decision that cannot be easily justified on legal and ethical grounds.

Such a decision cannot be justified through reference to the fact that individuals with a mental handicap may need support to make decisions. This is the case for many individuals whether or not they have a mental handicap. The fact that individuals may need support to make personal decisions is not a sufficient reason to establish procedures which deny decision-making status to them.

Given the validity of the principles of self-determination, autonomy, and dignity, and the analysis provided in this study, what standards can be justified to guide the choice and design of mechanisms for delivering financial and planning resources? This study suggests three basic standards for guiding this choice.

First, do the mechanisms create a status for the individual, such that the decisions made about choice of support, service provider, and management of personal decision making in ongoing service delivery, are substantially accountable to the individual?

Second, do the mechanisms provide standing to those designated by the individual to assist in making decisions? Further, where an individual is neither able to make nor articulate these decisions or designate decision-making status to someone, do the mechanisms acknowledge the status of those close family or friends who, based on their personal commitment, history, and relationship with the individual, are able to make decisions that reflect the wishes, goals, and interests of the individual?

Third, are the mechanisms based on an acknowledgement that these decisions are ones which involve negotiations between individuals, the funding agencies, and service providers, and that individuals or their representatives may require assistance in formulating plans and negotiating decisions?

The examination carried out in this study indicates that individualized funding and fixed point service brokerage are able, in their conception and basic design, to meet the standards which the principles of self-determination, autonomy, and dignity require. They provide the contractual status, the recognition and status to family and friends who can support an individual in making decisions, and the knowledge and expertise to assist the negotiation of decisions.

Finally, it is important to emphasize that self-determination, autonomy, and dignity are integral to individuals' quality of life. Public policy should ensure that the quality of life for individuals improves with their consumption of services and their participation in community support systems. This study suggests that public policy can play this role only if it is recognized that individual quality of life is affected by the funding and planning mechanisms in place; if there is clarity about the policy alternatives for these mechanisms; and if there are clear principles and standards for judging policy alternatives and for making policy choices.

APPENDIX A

METHODOLOGY OF THE STUDY

The study has assessed the impact of service brokerage and individualized funding on achieving the aim of self-determination, autonomy, and dignity for individuals with a mental handicap. "Decision-making opportunity" was selected for the purposes of this study as the measure of this aim. Chapter One outlined the conceptual framework for the evaluation. This appendix outlines the research methods.

Qualitative research methods were used in the collection and analysis of data. These methods were used in order to examine decision-making constraints and opportunities as they appeared in the experience of individuals and their families. As indicated in Chapter One, the parameters of decision making could not be fixed at the outset because few guidelines exist for program evaluation in which decision-making opportunity is the primary outcome measure. Consequently, more structured methods of data collection, beyond the open-ended interviews used in this study, were not appropriate to the task.

RESEARCH DESIGN

The research design for this evaluation was set in general terms at the outset of the study. The research team met with a group of parents, CLS staff, brokers, and Board members to clarify the organizational goals that would provide the basis for evaluation. It was agreed at the first meeting with this group that the opportunity to make decisions about community supports and services would be the basic measure of the goal of self-determination, autonomy and dignity.

A set of preliminary interviews were then held to test: (1) whether decision making was identified by individuals and families as an important dimension of quality of life; and (2) whether basic criteria of the opportunity for making decisions from the perspective of individuals and families could be identified. The preliminary interviews did yield data which met these tests.

On the basis of this data a "framework for evaluation" was designed. Data was collected through a series of in-depth and open-ended interviews with individuals, their families, support staff, CLS administration, Board members, service brokers, other service providers, social workers, and government officials.

SAMPLING

The sample for interviews with individuals and families was designed "purposively" rather than "randomly". In order to ensure that service brokerage and individualized funding would be examined for their impacts on the self-determination, autonomy, and dignity of a range of individuals, those who were included in the study varied across a number of criteria. These criteria included: the year individuals left Woodlands; funding sources (Ministry of Social Services and Housing, and Ministry of Health); extent of involvement of family and friends; the use of CLS residential and day services, and the use of services from other providers; and extent of individual need. Family members, and support staff involved with these individuals were then identified.

METHODS OF DATA COLLECTION

Review of documents

Documents analyzed included the administrative guidelines, historical records, agreements of the Community Living Society, government policy statements, and provincial reports concerning services and supports to individuals. As well, the general service plans of a selection of individuals brokered for by the CLS were reviewed.

Interviews

For the purposes of this study fifteen individuals were selected for detailed case studies of their history in institutional care and the community service system, their involvement with service brokers, the nature of the planning process under general service planning, and the ways in which decisions had been made concerning their services and supports in ongoing service delivery. Some of these individuals could speak for themselves and were interviewed. Many were not able to speak for themselves and so a combination of staff, family members, brokers, and administrators were interviewed. The researchers spent time visiting ten of the residences of the CLS, sometimes two or three times, where a total of thirty-nine individuals lived. Three of the CLS "day mods" or vocational service settings were also visited to meet with staff and individuals. Twenty interviews were held with parents of individuals who have been brokered for by the CLS.

Twenty-five in-depth interviews were held with support staff in residential and vocational services managed by the CLS. These interviews provided information about the experiences of a select sample of individuals, for whom detailed case studies were undertaken. These interviews also provided information about a number of other individuals served by the support staff.

Administrators and support staff at four non-CLS service agencies were also interviewed. Individuals brokered for by the CLS received services from two of these agencies.

Over the course of the study, numerous interviews were held with current CLS brokers, as well as two past brokers, the executive director of the CLS, and other administrative staff. These interviews concerned particular individuals served by the CLS, as well as the procedures by which partially and fully implemented fixed point service brokerage and individualized funding were managed.

In addition, two social workers, two senior officials in the Ministry of Social Services and Housing, three senior officials in the Ministry of Health, and a senior administrator at Woodlands were interviewed. These interviews provided data with which to clarify the procedures used under the different mechanisms for delivering financial and planning resources.

DATA ANALYSIS

Analysis in qualitative research usually proceeds by coding the data based on the themes that emerge through the research process in the field, and that are present in the accounts from the interviews. Although the themes or categories cannot be established at the outset, the key questions to guide the analysis need to be established early in the research process. The questions used to structure the research design and to guide the analysis presented in this report include:

- What are the kinds of decisions people want to be able to make with respect to supports and services?
- What are the criteria for decision-making opportunities?
- What were the impacts of decision-making procedures and processes prior to individuals' and families' use of brokerage and individualized funding?
- What were the impacts of the procedures under partially and fully implemented service brokerage and individualized funding?

The analysis of the research data against these questions began with the preliminary interviews and continued throughout the data collection and final stages of analysis. As themes began to emerge from the research, partial and provisional answers were formulated, only to be re-formulated as the analysis progressed.

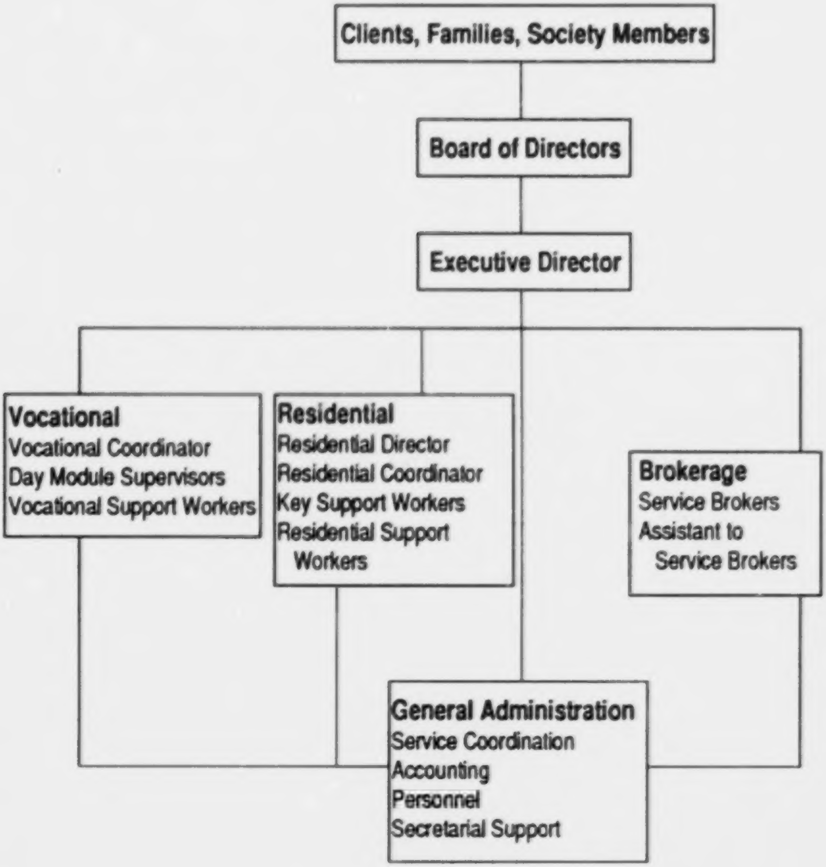
The key decisions that individuals and families wanted to be able to make were first organized under the categories of housing, work, recreation, etc. It was only when the analysis was shifted from this categoric approach, to the systemic barriers to individuals' and families' decision-making opportunity, that the nature of the decisions they wanted to be able to make became clearer. One after another identified common barriers to decision-making: individuals' and families' needs for support were often defined for them; their service providers were designated by others; and decisions about ongoing service delivery were often made by the service provider. These barriers came to signify where individuals and families most wanted decision-making opportunity.

The criteria for decision-making opportunity were identified only through an ongoing process of data analysis. Although they may seem self-evident, it was important in the research process to ensure that they emerged from the data, and not from categories imposed by the researchers. The choice of criteria is a critical one. It was the assumption in this study that the criteria of decision-making opportunity had to be identified by those for whom the extent of decision-making opportunity was being measured.

APPENDIX B

Figure 1

Organizational Structure of the Community Living Society (1989)


Clients, Families, Society Members
Board of Directors
Executive Director
Vocational
Vocational Coordinator
Day Module Supervisors
Vocational Support Workers
Residential
Residential Director
Residential Coordinator
Key Support Workers
Residential Support Workers
Brokerage
Service Brokers
Assistant to Service Brokers
General Administration
Service Coordination
Accounting
Personnel
Secretarial Support

APPENDIX C

COSTING THE GENERAL SERVICE PLAN

Costing the General Service Plan (GSP) involves: (1) assessment of physical, social and psychological needs; (2) translation of these needs into specific goods and services; and (3) costing of these goods and services.

In costing the GSP, both basic and special needs are taken into account. The physical costs of living are determined by a range of factors including rent or mortgage (depending upon whether the residence will be purchased or rented), the cost of staff supports, and operating costs.

SHELTER EXPENDITURES

Shelter expenditures — a major component of the budget — are determined by the actual housing costs. Factors such as whether the residence is owned or rented by the CLS, location of the dwelling, and associated property tax implications affect the costs in this category. The budget entries of heat, hydro, cable television, telephone, maintenance and repairs, and replacement reserves are relatively standard items to cost.

SUPPORT STAFF

By far the most difficult aspect of the costing is the residential support services. A determination must be made as to how much support an individual requires based on both the extent of his or her needs as well as the number of hours for which such support is required. In the case of someone who has challenging needs (i.e., that person might require the help of someone who has specialized nursing training), the cost of the service would be higher because of the higher hourly rate paid to the staff person, and/or the greater number of hours required.

In costing the support services, it is assumed that there has to be one key support worker in each home. Staffing over and above this basic service is then determined according to the individual who has the greatest needs. In other words, the "highest common denominator" is used as the starting point.

It is assumed that if the staff requirements of the individual with the most challenging needs are met, the needs of others can be met as well, either through this core staff person or with some additional help. It would not be a wise practice to submit a budgetary estimate on the basis of the "lowest common denominator" (i.e., on the basis of the least challenging needs), only to find out later that the residence is seriously understaffed. Requesting additional staff because of an incorrect assessment can be difficult to negotiate.

For the majority of individuals served by the CLS, who live in residences with three or four other individuals and who require twenty-four-hour supports, costing has to be carried out on the basis of the needs of the members of a group. The costing is individualized to the extent that each person's needs are examined from the perspective of what he or she requires; those needs are then juxtaposed against the requirements of other members of the group. For example, estimates for the costs of a support worker are formulated according to the number of hours that would be required by each person as well as the number of hours that can be shared by them all.

Once an estimate for staff costs is made, a certain percentage is incorporated over and above the basic amount for benefits as well as for coverage of unanticipated events such as replacement staff for days when regular staff are sick.

The staffing costs are essentially the only flexible portion of the budgeting process because certain items such as mortgage or insurance costs are fixed and receiptable. Other items, such as food, are budgeted within standard parameters unless there are exceptional needs as in the case of special dietary requirements.

Funding sources make no allowance for cost of living increases or vacation time for residential staff. In order to cover these costs, the CLS builds a certain percentage float into the staff support category.

OPERATING COSTS

Costs for items such as food, entertainment and laundry are estimated on the basis of reasonable expenditures for these items. This is, necessarily, a subjective assessment. At the same time, those applying for the funding know that there are certain parameters within which funding bodies operate. It is understood that these parameters cannot really be exceeded unless very special needs warrant such expenditure (e.g., the individual has a special dietary requirement that would drive up the cost of food). A general parameter that is kept in mind when costing operational items is that the government bases its guidelines for expenditures on certain standards. In the case of food, for example, the B.C. government employs the Canada Food Guide as a standard for a healthy diet and specifies a per diem rate based on this standard.

In the case of equipment and other technical aids, the costs assigned to these items are based on *actual costs*. For example, a communication board may be estimated at $500. The GSP would include cost estimates for both the *initial outlay* required to purchase the specific item as well as a yearly replacement reserve. This is to ensure that funds will be available for repair or replacement of the equipment.

VOCATIONAL SUPPORTS

Because the individuals living in CLS homes are expected to be out during the day, a specialized plan must be developed for each person which includes a combination of the following possible activities: life skills training; recreation; and vocational training. Costs are assigned to each of these services. The CLS operates six vocational modules in different locations in the greater Vancouver area; these are supervised by three staff persons. The modules act as the focal point for carrying out vocational assessment and identifying the most appropriate program for each individual.

An estimate of operating costs (overhead, transportation, training) is obtained first. Monthly overhead costs are calculated by determining the total required for rent, utilities, telephone supplies and equipment. A small amount is budgeted for staff training and development. Monies are set aside for transportation costs when individuals are unable, for whatever reason, to use public transportation.

The second component of the budgeting process involves the identification of the number of hours of support each individual, as well as the "cluster" as a whole, will need every month. Individuals often require a different number of hours of support reflecting their varying levels of need.

APPENDIX D

INDIVIDUALIZED FUNDING IN RELATION TO THE CANADA ASSISTANCE PLAN

by Sherri Torjman

INTRODUCTION

The purpose of this technical appendix on individualized funding is to answer one important question. Within current financing arrangements in this country, is it possible to put in place a system of individualized funding to meet the needs of persons with disabilities?

The simple answer is yes. In fact, there is already an income program in every province and territory which operates on the basis of individualized funding.

However, the simple yes answer must be qualified. Under the existing funding mechanisms, it is relatively easy to individualize dollars for certain goods and services only. Other goods and services present a challenge from a funding perspective and their support cannot be easily translated into a personalized approach.

This technical appendix is divided into several sections which address the following questions pertinent to the major theme:

- What is individualized funding?
- What models of individualized funding are currently in place?
- What is the Canada Assistance Plan? How does it provide for the funding of disability-related goods and services?
- Can a system of individualized funding be supported under the Canada Assistance Plan?
- What are the other major sources of funding for disability-related goods and services? Could these goods and services be provided through some form of individualized funding?

The conclusion ties together the highlights of this technical appendix. It summarizes how individualized funding is possible within current funding arrangements — as long as certain requirements and conditions are met.

WHAT IS INDIVIDUALIZED FUNDING?

Individualized funding is a very simple concept. It refers to the provision of money directly to individuals to help them meet their basic and special needs.

The notion of individualized funding is based upon the following principle: persons with disabilities need income for two major purposes. First, they require money for basic living needs such as food, clothing, shelter and utilities. Second, they require money for their special disability-related needs (e.g., medications, equipment), and for services (e.g., homemaker assistance, life skills training or attendant care).

Under current funding arrangements, basic needs are generally compensated through the provision of cash assistance. Special needs, by contrast, are compensated through the provision of cash, goods and/or services.

In theory, a model of individualized funding means that individuals would receive a cheque from government which represents the total of their basic and special needs. All needs would be compensated in dollars. From this money, individuals would purchase the goods and services they require to meet their basic and special needs.

Publicly supported services would still be in place. However, their funding base would shift as their support would be derived partially from direct government subsidies and partially from the dollars of the individuals purchasing the services. These would no longer be supported primarily through direct government subsidies.

WHAT MODELS OF INDIVIDUALIZED FUNDING ARE IN PLACE?

A form of individualized funding is already in place in this country. The allocation of funds to individuals to provide for their basic and special needs very closely resembles the existing welfare system.

The welfare system is administered at the provincial and territorial level (as well as at the municipal level in Nova Scotia, Ontario and Manitoba). It is governed in every jurisdiction by a unique set of rules.

Despite the individual differences in welfare systems, they all carry out a similar function. They provide money, goods and/or services to persons who qualify for this assistance. A monthly cheque is paid to eligible individuals and families to cover their basic living needs. An additional amount may be allocated for special assistance where required. Certain services are provided to eligible individuals and families at partial or no cost.

How would individualized funding differ from a program which already compensates individuals for their basic and special needs?

There are a number of problems which make the current welfare system an ineffective program for meeting the needs of individuals with a mental handicap. Under provincial and territorial welfare programs, all persons who receive monthly cheques are considered to be "recipients". They play a passive role and basically accept the assistance for which a welfare worker has deemed they are eligible.

Most recipients have little information with respect to their potential entitlement. The lack of information is particularly problematic for persons with special needs because of the way these are compensated.

The costing of basic needs is carried out in a relatively standard way (even though the specific method varies by province). There are certain guidelines or parameters which must be followed in the calculation of benefits. Generally, maximum allocations are designated for food, clothing, shelter, utilities and personal allowances.

Special needs, by contrast, are provided for on a discretionary basis. Individuals must make a request for assistance for special needs. The request must be approved by a welfare worker, director, physician or other designated authority.

Applicants and recipients are often unaware of the availability of special assistance or of the maximum amounts to which they may be entitled. As a result, many individuals do not receive help for a special need or may receive only a limited amount which is inadequate to cover their extra disability-related costs.

Individuals with special needs also experience difficulties under the current arrangements because these needs are often addressed through the provision of a particular item or a service rather than through cash assistance. The result is that if there is no program in place to provide the required goods or service, then their special needs are not met.

Say, for example, that an individual requires help in learning basic life skills. There is no guarantee under the current system that this need will be met. There may be no such program available in the community. If one does exist, it may be full and may have an extensive waiting list. Another possibility is that the person may not qualify on the basis of the eligibility criteria set out by the program. The result is that the individual is unable to obtain or does not have access to the required service.

Yet another problem encountered by individuals with disabilities, in particular, is that a certain service may be available but is delivered only in a designated setting such as the home. Persons who require the service in settings other than their homes — such as in workplaces, training programs or recreational facilities — may find that they are refused service because their need moves beyond the narrow limitations of service delivery.

Individualized funding would overcome many of the problems associated with the provision of assistance for special needs. This type of funding would allow the prospective recipient to play a key role in identifying his or her special needs and how these should be addressed. An individual may feel, for example, that a certain service is not the most effective way to meet his or her personal care needs. There may be another way of responding to these needs and the individual would participate actively in determining the most appropriate solutions.

The provision of dollars directly to individuals would also help overcome many of the problems inherent in the existing network of services. For example, arrangements could be made to purchase services privately when these are not available in the community or when these are inappropriate to meet a person's needs. Individuals could purchase a service which would be provided in whatever setting it was required. The actual locale of the delivery would no longer be determined by the service providers but by the person purchasing the service.

It is important to recognize that individualized funding would have a significant impact upon the funding of services in particular. Such a funding system would essentially involve at least a partial shift from the support of services to the support of the individuals who require those services — a shift from supply-side to demand-side funding. The implications of such a shift (e.g., concerns about privatization; about service instability if core funding is withdrawn) are noted although not considered here.

In summary, there are significant parallels between existing welfare programs and individualized funding. If properly implemented, however, the latter would represent a significant improvement — especially in its capacity to respond to and provide for special needs. It would be a much more effective way of meeting the needs of persons with a mental handicap.

Whether individualized funding would provide more adequate assistance (in terms of higher levels of benefits) than the current welfare system depends upon the level of funding allocated to the program.

THE CANADA ASSISTANCE PLAN

The purpose of this section is to describe the Canada Assistance Plan (CAP). The next section will explore whether CAP can be used to support a system of individualized funding.

The Canada Assistance Plan is the primary mechanism in this country for financing the costs of social assistance (welfare) and of certain services. It allows the federal government to pay 50 percent of the costs of the assistance and/or services provided to persons in need or likely to be in need.

The Canada Assistance Plan Act is divided into three parts. Under Part 1, there are two funding streams: the assistance provisions and the welfare services provisions. Each stream is described below. It will be seen that the assistance provisions are particularly relevant to individualized funding.

In the following discussion, the term "Act" refers to the Canada Assistance Plan Act.

Assistance provisions

Basic requirements

Under the assistance provisions, provinces/territories and municipalities can make available "assistance" or "aid in any form" to persons in need to meet their basic requirements. These are defined in Section 2(a) of the Act as "food, shelter, clothing, fuel, utilities, household supplies and personal requirements".

Special needs

Section 2(b) of the Act also allows assistance or aid in any form to be provided for "prescribed special needs of any kind". These special needs of any kind are defined further in Sections 4(b)(i), (ii) and (iii) of the Canada Assistance Plan Regulations.

Under Section 4(b)(i) of the Regulations, special needs of any kind include "any item necessary for the safety, well-being or rehabilitation of the person in need, including essential household equipment and furnishings, essential repairs, alterations and additions to property; and items necessary for a handicapped person". The cost of any item, however, cannot exceed $500 in a year unless approved, either before or after the item is provided or provided for, by a designated provincial authority.

Section 4(b)(ii) of the Regulations allows for the provision of any of the following items where these are required for the safety, well-being or rehabilitation of the person in need: special food or clothing; telephone; or rehabilitation allowances and housekeeping allowances. In contrast to the previous section, there are no prescribed limits on these expenditures.

Finally, Section 4(b)(iii) permits the costs of "special care necessary for the safety, well-being or rehabilitation of a handicapped person in need".

The costs of special needs items required for work — e.g., fees or permits; special clothing; tools or other equipment — may also be shared under the assistance provisions of CAP.

Prescribed services

Under Section 2(g) of the Act, assistance can be provided to persons in need in the form of "prescribed welfare services purchased by or at the request of a provincially approved agency". These prescribed welfare services are defined more explicitly in Section 5 of the CAP Regulations as: rehabilitation services; casework, counselling and assessment services; and homemaker, day care and similar services. The services must be purchased on a fee-for-service or unit cost basis on behalf of a person in need.

When a prescribed service is provided to an eligible individual or family by a private non-profit or commercial agency, shareable costs are based upon the fees charged by the agencies. When services are provided by a provincial/territorial or municipal agency, shareable costs are based on the actual cost of providing the service.

The services authorized under the assistance provisions of CAP may be provided by any type of agency. There is no requirement that the agency be a non-profit or licensed organization (there are such requirements under the welfare services provisions described below). The federal contribution is made only on behalf of an individual who qualifies on the basis of a needs test — i.e., who is a "person in need".

"Person in need"

Section 2 of the Act defines "person in need" as a person who, by reason of inability to obtain employment, loss of principal family provider, illness, disability, age or any other cause acceptable to a provincial authority, is found to be unable to provide adequately for him or herself and/or his or her dependents. This inability must be determined on the basis of a test established by the provincial/territorial authority that takes into account a person's budgetary requirements as well as the income and resources available to meet those requirements. In other words, federal funds can be shared under CAP only if the assistance (for basic requirements, special needs or prescribed services) is provided to individuals who qualify on the basis of a needs test.

The needs test involves an examination of applicants' assets and of their needs and resources. First, the value of their liquid assets (e.g., cash, bonds) and fixed assets must fall below certain designated levels. Second, their needs must exceed the resources available to them through employment-related income, public or private pensions, or other sources. As a result, they have a budget deficit.

With respect to liquid assets, in particular, the Liquid Asset Exemption Guideline under the Canada Assistance Plan sets out the maximum levels of liquid assets that CAP will recognize for cost-sharing purposes. While provinces/territories are free to set their own asset exemption regulations, the federal government will share in the costs only for those applicants whose liquid assets do not exceed the following parameters:

- up to $2,500 for a single person and $3,000 for a person who is aged or disabled;
- up to $5,000 for a person with one dependent (a couple and/or a single parent with one child) and $5,500 when the applicant and/or spouse is aged or disabled;
- an additional $500 for the second and each additional dependent;
- an (unspecified) additional amount where the money has been placed in a trust arrangement for purposes which the province deems socially important;
- an (unspecified) amount which senior provincial officials may allow for applicants with extraordinary circumstances.

In addition to limitations on assets, the assistance provisions require that applicants qualify for assistance on the basis of a needs test. That is, they must have a budget deficit as described below.

Say, for example, that a single-parent family with a young child had the following monthly basic needs:

Food	$250
Shelter	450
Clothing	65
Fuel	60
Utilities	40
Household Supplies	25
Personal Requirements	25
TOTAL MONTHLY NEEDS:	**$915**

The total monthly basic needs of this family are $915. The parent earns only $200 a month from casual employment. The family also receives the family allowance, child tax credit and sales tax credit from the federal government but these amounts are considered exempt in the calculation of income.

In this case, the family's needs ($915 a month) exceed its resources ($200 a month). The family has a budget deficit of $715 ($915 minus 200). This family would be considered to be "in need" and would be eligible for assistance.

Other assistance

The definition of "assistance" in Section 2 of the Act also includes "health care services" and the care provided in a "home for special care". These two types of services used to be funded like other CAP services. However, they are no longer subject to fifty-fifty federal/provincial cost-sharing.

The funding of health care services and of the care provided in homes for special care has been substantially modified since the introduction of the enabling legislation for the funding of health care services — the Federal-Provincial Fiscal Arrangements and the Federal Post-Secondary Education and Health Contributions Act, 1977. (The funding arrangement is sometimes referred to as EPF — Established Programs Financing). The Act allows federal contributions for health and post-secondary educational services to flow to provinces and territories in the form of a block amount calculated on the basis of a predetermined formula. Health care funding is described more fully in the final section of this appendix.

With respect to health-related goods and services, the effect of EPF funding has been to limit CAP cost-sharing to items that are not funded under the EPF arrangement. For example, eligible individuals (i.e., those who qualify on the basis of a needs test) may require the following types of health-related goods or services:

medication, ambulance transportation, audiology services, dental health services, speech therapy or occupational therapy. These health-related goods and services are not covered under EPF block financing arrangements and are shared under CAP as non-EPF health care costs.

In the case of residential care provided to adults in homes for special care or supervised facilities, CAP now shares only in the costs of the "social" component of the care. This social component refers to a comfort allowance, a clothing allowance, non-EPF health care costs as described above and an amount attributable to room and board. CAP also shares in the costs of any special health-related items an individual may require.

This means that the assistance provisions allow CAP to share in certain health-related and residential care costs but only as strictly defined in the guidelines which govern the "interface" between CAP and EPF. In general, CAP shares only in non-EPF health care costs — those health-related costs not covered under the general health care financing mechanism. In addition, CAP sharing is limited to the costs incurred on behalf of eligible individuals.

It should be noted that CAP continues to share all the residential care costs for children in need.

Summary of assistance provisions

Assistance may be provided for basic needs, special needs and prescribed services. Assistance for basic needs generally takes the form of direct payments to persons in need. In the case of special needs, assistance may be provided as money, as particular goods such as a set of eyeglasses or as services such as homemaker assistance. The Act allows cost-sharing, however, only on behalf of a "person in need" as determined by a needs test administered by the province or territory.

"Assistance" also includes certain health-related and residential care services. CAP plays a residual role in the funding of these services (except in the case of residential facilities for children where it continues to share 50 percent of the costs).

Welfare service provisions

Cost-sharing is also permitted under the welfare services provisions of CAP. In this case, funds are not transferred to individuals. These provisions are basically a means of allowing the flow of funds to services.

The welfare services provisions will be described here simply for information purposes. These provisions allow the flow of funds only to agencies — not directly to individuals or to families. The welfare services provisions could therefore not be used to support a system of individualized funding.

Section 2 of the Canada Assistance Plan Act defines "welfare services" as "having as their object the lessening, removal or prevention of the causes and effects of poverty, child neglect or dependence on public assistance". These services include, but are not limited to:

- rehabilitation services;
- casework, counselling, assessment and referral services;
- adoption services;
- homemaker, day care and similar services;
- community development services;
- consulting, research and evaluation services with respect to welfare programs;
- administrative, secretarial and clerical services including staff training relating to the provision of any of the above services or to the provision of assistance.

Welfare services do not include services related primarily to education, corrections, health care (with the above-noted exception for CAP residual funding), recreation, cultural activities, school social services, hospital social services, mental health services and court-related services.

While the assistance provisions require individuals to qualify on the basis of need, the welfare services provisions of CAP allow services to be provided to those "in need" (as defined above) or to "those likely to be in need". The latter is intended for preventive purposes — i.e., to allow the delivery of services to households that may not qualify on the basis of need, but that may be in danger of slipping into poverty or experiencing serious problems if these services are not available to them.

Households are considered likely to be in need if their net income falls below certain levels. According to the Guidelines on Likelihood of Need, persons or families likely to be in need must qualify for services on the basis of a provincial/territorial income test or must be recipients of the federal Guaranteed Income Supplement (which itself requires qualification on the basis of an income test).

While provinces and territories may develop their own income tests, Ottawa sets guidelines for the net income levels used in determining likelihood of need. The federal government will not share in the costs of welfare services provided to individuals or families whose net incomes exceed the federal guidelines.

A household with a net income below a designated "turning point" is eligible for a full subsidy (i.e., pays no fee for the service). In the first quarter of 1990 (January to March), the turning point was $13,776 for a single person, $27,552 for a single-parent family with one child and $36,744 for a two-parent family with two children. These levels are adjusted quarterly in line with increases in the federal Old Age Security/Guaranteed Income Supplement.

Households with net incomes above the turning point pay part of the cost of the service until the "break-even level", i.e., the point at which the subsidy ends. During January to March 1990, the break-even level was $20,664 for a single person, $41,328 for a single-parent family with one child and $55,116 for a two-parent family with two children. Using these federal guidelines as parameters, provinces and territories set their own turning points and break-even points for the income tests they administer to determine eligibility for welfare services.

It is important to note that the welfare services provisions also allow for a certain target group or geographic community to be designated as a "community of need". Needs testing or income testing of individuals can be replaced by proxy indicators. CAP will share in the costs of welfare services provided to members of a community of need if the indicators demonstrate that most, if not all, members of the community are in need or likely to be in need.

A significant outcome of the recent Federal-Provincial Review of Fiscal Arrangements Affecting Persons with Disabilities was the agreement to change the likelihood-of-need policy to facilitate procedures for cost-sharing under the welfare services provisions of CAP. When individuals require services that are disability-specific, such as attendant care, they will be considered as persons likely to be in need.

One of the major differences between the assistance provisions and the welfare services provisions is that services are eligible for cost-sharing under the welfare services stream only if they are provided by a provincially-approved agency. Unlike the assistance provisions, commercial agencies are excluded from this definition.

The CAP Regulations and Notes on Welfare Services under the Canada Assistance Plan spell out the costs which are shareable under the welfare services provisions. Shareable costs include, for example, staff salaries, fringe benefits, travel and training. Capital costs, by contrast, are not shareable although depreciation allowances are permitted for certain designated items.

Summary of welfare provisions

The welfare services provisions of CAP allow for the sharing of costs incurred by welfare services, as these are defined in the CAP Act. Services must meet certain criteria — they must be non-profit agencies. Only designated costs such as staff and salary are covered. Furthermore, CAP will share only in the costs of services provided to applicants who qualify on the basis of a needs or income test. A target population or geographic area may also qualify as a community of need.

The welfare services provisions cannot be used to support a system of individualized funding. These provisions do not permit the flow of funds to individuals.

CAN INDIVIDUALIZED FUNDING BE SUPPORTED UNDER *CAP*?

The Canada Assistance Plan can support individualized funding. However, such a system could be funded only under the assistance provisions of CAP. These are the provisions that allow the flow of funds to individuals and families. The welfare services provisions, by contrast, allow the flow of funds to services and therefore could not support a system of individualized funding.

As previously described, the assistance provisions allow the cost-sharing of funds for basic requirements, for special needs items and for prescribed services as defined in the CAP Regulations. In short, the Act permits the cost-sharing of funds paid to individuals for their basic needs as well as for special items and services.

In practice, special needs items and services have not generally been provided for in the form of cash. They are most often provided as income-in-kind. The actual item is either given to the person (e.g., special eyeglasses), the required item is paid for through a voucher or other method (e.g., a drug card is issued), or a service is provided or paid for on the person's behalf (e.g., homemaker services).

There is nothing in the CAP Act or Regulations, however, that actually precludes the direction of funds to individuals themselves. In fact, the Act explicitly defines "assistance" as "aid in any form".

While provinces/territories may have chosen to provide assistance in the form of an item or service, there do not appear to be any legislative or regulatory roadblocks to the provision of assistance entirely in cash. It is likely that provinces/territories have resorted to the provision of income-in-kind as a control measure to ensure that the assistance is actually used for the purpose for which it was intended.

While the assistance provisions permit the flow of funds to individuals, there are a number of factors that must be taken into consideration when employing these provisions. These relate to: the needs testing requirement; the purchase of prescribed services only; the reimbursement for service; limitations on expenditures for special needs items and other funding limitations. Each of these factors is discussed more fully below.

Needs testing requirement

The assistance provisions require that individuals qualify for assistance on the basis of a needs test. They must have assets that fall below certain designated levels as well as a budget deficit — that is, their needs must exceed the resources available to them.

The needs testing requirement is very important. It is central to the flow of funds under the assistance provisions. It means that there must be an administrative mechanism in place which conducts the needs test. Under the current welfare system, welfare workers in local income security offices determine an applicant's eligibility on the basis of their needs. There is a built-in administrative complexity associated with needs testing.

The requirement for a needs test would not necessarily create problems for individualized funding because the latter is based on individual negotiation of need. The system would thereby build in a needs test of sorts.

The implications of needs testing are significant, however, in that individuals could not qualify for assistance simply on the basis of an income test, e.g., a measure only of their level of income. Such tests are used for determining eligibility for the Guaranteed Income Supplement (GIS) for low-income seniors and the child tax credit for low-income families with children. In the latter case, the tax system acts as the income test for this refundable credit.

Income tests are also employed in determining eligibility for services funded under the welfare services provisions of CAP. The current turning points and break-even points based on levels of net income were earlier described.

Provision of service

There are certain requirements pertaining to services in particular. The assistance provisions of CAP allow only the purchase of prescribed services. As previously indicated, these services are prescribed in Section 5 of the CAP Regulations and include: rehabilitation services; casework, counselling and assessment services; and homemaker, day care and similar services.

The definition of prescribed services is broad in scope and likely includes most services that would be required by persons with disabilities. If, however, the required service does not fall within the definition of a prescribed service, then it could not be purchased through individualized dollars under the assistance provisions.

The assistance provisions of CAP also require that the prescribed services intended for a particular individual be purchased by or at the request of a "provincially approved agency". If this provision were applied to a system of individualized funding, it would mean that an agency designated by the province or territory would have to approve any expenditures intended for services.

In theory, this requirement should present no serious obstacles. A system of individualized funding would involve a process of negotiation with a provincial/territorial representative to determine individual need. This could be the means of ensuring request of purchase by a provincial/territorial authority.

At the same time, however, this provision could be problematic. Individuals may find that their ability to make decisions regarding the best way to meet their service needs is relatively limited, especially if the designated authority disagrees with the choice of service.

A positive feature of the assistance provisions should be noted. They are less stringent than the welfare services provisions in terms of the types of services that they will fund. This means that services can be secured from a private individual or commercial agency in addition to a non-profit organization. There is greater choice in terms of the types of services that an individual may purchase.

Reimbursement for services

The assistance provisions require that the eligible costs for services provided by non-government agencies, including both commercial and non-profit service providers, are based upon the fees charged by these agencies. When the services are provided by a government agency (e.g., a municipality), the agency costs are reimbursed. Agency costs are also eligible for sharing under the welfare services provisions of CAP. These cost-sharing technicalities would not make much difference to the individual who would still receive the service whether or not governments reimbursed agency fees or agency costs.

The funding mechanisms do have implications, however, for the stability of services. There is some concern that a shift in the funding of services from the welfare services provisions (direct support of agency costs) to the support of services under the assistance provisions (indirect support of agencies through the cost-sharing of agency fees) would destabilize the funding base of services. Agencies would have to function more on the basis of a free market approach in which their costs are supported through fees paid by users.

The counter-argument, however, is that the current funding arrangements have not required agencies to be particularly responsive to needs. A shift in funding may encourage if not force them to be more needs-responsive.

Limitations on expenditures

The assistance provisions of CAP provide for the cost-sharing of a wide range of special needs items. As indicated in the previous section, these include any item necessary for the safety, well-being or rehabilitation of a person in need including "items necessary for a handicapped person".

Section 4(b)(i) of the CAP Regulations, however, places limitations on certain expenditures. It stipulates that the cost of providing, or providing for, essential household equipment and furnishings, essential repairs to property and items necessary for a handicapped person cannot exceed $500 unless the expenditure is approved by an authority designated by the province or territory.

There is no stated limit, however, for the following items: special food or clothing; a telephone; rehabilitation and housekeeping allowances; or for any special care necessary for the safety, well-being or rehabilitation of a handicapped person in need.

In short, the only effective limitation that the Regulations place on expenditure for special needs items relates to property repair and to "items necessary for a handicapped person". Presumably, the latter refers to items such as prosthetic/orthotic appliances, special equipment and communication-related devices such as a hearing aid. It is important to note that the Regulations do not state that the amount will not be paid; they simply require approval by a designated authority for expenditures that exceed that amount.

In theory, this provision might create difficulties for certain individuals who are refused a particular item on the grounds that it is too costly. While this is possible, it is hoped that provinces and territories use the provision more as a check on a large expenditure rather than as a means of refusing essential items that an individual requires for his or her safety, well-being or rehabilitation.

Limitations on other expenditures

One of the important yet unexplored aspects of individualized funding is whether the person who purchases the services actually becomes the employer of the service provider. If so, there are associated costs such as the employer contribution to Unemployment Insurance premiums and to the Canada/Quebec Pension Plan. This would mean that an extra amount would have to be built into the funds provided to the person to pay for these costs.

CAP provisions only take this into account by reimbursing agency fees which presumably incorporate these employer costs. If, by contrast, the individual used the dollars to hire a private individual not affiliated with an agency, it is unclear how the employer costs would be handled.

While there are other questions that need to be addressed with respect to the status of this employment relationship, these are beyond the scope of this paper.

Summary

Individualized funding in the form of cash assistance for basic requirements, special needs items, and certain prescribed services is possible under the assistance provisions of CAP as long as certain conditions are met. These conditions include: the determination of eligibility on the basis of a needs test, the purchase of prescribed services only by or at the request of a provincially approved agency, designated methods of reimbursing service costs, and administrative approval for the purchase of certain items "required by a handicapped person" that exceed $500.

There are, however, a range of services required by persons with disabilities that are not funded (or are only partially funded) by CAP. The question then arises as to whether it is possible or in some cases even desirable to individualize dollars for the purchase of these services. The next section will address this question by examining the sources of funding for related services in the areas of health care, education, vocational rehabilitation and housing.

HOW RELATED SERVICES ARE FUNDED

This section describes the funding sources of related services in the areas of health care, education, vocational rehabilitation and housing. It attempts to address the question of whether these services can be supported through some form of individualized funding.

There is no simple answer to this question. Under current funding arrangements, certain services can be supported through individualized funding while other services cannot.

Health Care

Health care services are regulated under the Canada Health Act which came into effect in 1984. The Act is administered by the Department of Health and Welfare.

The Canada Health Act repealed the Hospital and Diagnostic Services Act (referred to in Section 2 of the CAP Act) and the Medical Care Act. There are two major kinds of health care services defined in the Canada Health Act: insured health care services and extended health care services.

Insured health care services refer to the medically necessary hospital services, medically required physicians' services and surgical or dental services that require a hospital for their proper performance. Extended health care services refer to: (1) ambulatory care, i.e., health care services provided in an out-patient setting or in a private home; and to (2) health-related and nursing care provided in a long-term residential facility. An institution for persons with a mental handicap, for example, would qualify as an extended health care service if extensive supervision and care were provided in that facility.

The Canada Health Act sets out five criteria which govern the provision of insured health care services throughout the country. These five criteria are: comprehensiveness, universality, portability, public administration and accessibility. These five criteria must be met in order for provinces and territories to receive the federal contribution for health services. It is important to note that these five criteria do not apply to extended health care services. In other words, ambulatory care and long-term residential facilities are not governed by these criteria.

While the Canada Health Act sets out the criteria which govern the delivery of insured health care services, these services are actually funded under the Federal-Provincial Fiscal Arrangements and Federal Post-Secondary Education and Health Contributions Act of 1977 (formerly called the Federal-Provincial Fiscal Arrangements and Established Programs Financing Act). This Act is administered by the Department of Finance.

Under the Act, funds designated for insured health care services, in particular, are determined on the basis of equal per capita federal health contributions which are indexed annually in relation to increases in the Gross National Product (GNP) minus two percentage points. (The February 1990 budget froze the per capita entitlement for a two-year period). Actual contributions to the provinces and territories are made in the form of a cash transfer, (i.e., a direct transfer of funds) as well as through a transfer of tax points (i.e., an increase in the amount of tax which individual jurisdictions are permitted to collect).

In addition to cash and tax transfers, provinces and territories receive an equal per capita grant to help pay for the costs of extended health care services. The per capita payment of $20 was initially set in 1977-1978. The payment is increased annually by the average three-year rate of growth of the GNP minus two percent (frozen in February 1990).

The EPF fiscal arrangement is generally referred to as "block funding" because monies are transferred as a block by the federal government to the provinces/territories on the basis of a set formula. In contrast to CAP, which shares 50 percent of eligible costs, the EPF federal contribution does not vary on the basis of the type or extent of service provided by the province or territory.

The EPF funding arrangement "interfaces" with CAP funding in certain circumstances. Persons with disabilities are likely to be affected by this CAP/EPF interface in that they are often recipients of the services funded in this way.

As previously explained, the definition of assistance in Section 2 of the CAP Act includes "health care services" and services provided in "homes for special care". In the case of health care services, CAP will share, on behalf of eligible individuals only, in the costs of certain types of health-related goods and services. These are the goods and services not included within the meaning of "insured health care services" in the Canada Health Act.

The CAP provisions, with respect to "homes for special care" in particular, have been considerably modified since the introduction of the per capita arrangement block-funded by EPF. The Extended Health Care Services Program under the Federal-Provincial Fiscal Arrangements and Federal Post-Secondary Education and Health Contributions Act includes the costs of services for adults in long-term residences or institutional settings. These include settings that provide intermediate nursing home care or adult residential care.

Prior to the introduction of the Extended Health Care Services Program, the federal government under the CAP assistance provisions shared in 50 percent of the costs of care delivered to eligible adults and children in residential care settings. The introduction of block funding for extended health care means that CAP-shareable costs for the provision of long-term residential care are much more narrowly defined.

CAP costs are now limited to the following aggregate or combined amounts of provincial/territorial and municipal expenditure for care provided in long-term care facilities:

- a comfort allowance
- a clothing allowance
- non-EPF health care costs (described earlier)
- a portion of the room and board — represented by the difference between the total of the above three components and the maximum monthly Old Age Security/Guaranteed Income Supplement.

As of January to March 1990, the Old Age Security/Guaranteed Income Supplement (OAS/GIS) monthly maximum was $744.00. This amount may be exceeded if the eligible individual requires an item of special need such as dentures, eyeglasses, a hearing aid, orthodontic appliances or a wheelchair.

The details of this funding arrangement are outlined in the relevant cost-sharing guidelines. The important point for the purposes of this discussion is that the cost of long-term residential care in certain facilities is funded through a combination of health and social welfare dollars. This has significant implications for individualized funding.

Insured health care services are covered under the block. Funds are directed toward the services rather than toward the individuals who require the services. The latter are funded en masse in relation to per capita population of the relevant jurisdiction and not in relation to the individuals who require them on the basis of demonstrated need.

Because of the block-funded arrangement, it is not possible to individualize dollars for insured health care services. Besides, there should be no need to do so. These services are governed by the accessibility criterion in the Canada Health Act and must therefore be accessible to all residents of any given province or territory.

The situation is more complex, however, for extended health care services — in particular, those services that provide care in a long-term residential facility. In this case, CAP shares a certain portion of the costs on behalf of eligible individuals. Costs for the remainder of the care — which is primarily of a health-related nature are supported through health dollars provided under the block. It would be difficult to individualize these dollars because all costs which exceed the monthly maximum OAS/GIS payment (except for special needs items) are deemed to be health or EPF costs. Again, the latter funds are directed toward services and not to individuals.

It is possible, however, to question this use of funds. If the federal and provincial/territorial governments are sharing costs for an individual up to the OAS/GIS maximum within an institutional setting, why could they not share these costs to support that same person in the community? Part of the answer is that these individuals are deemed to require the health-related care and supervision provided in adult residential facilities. However, this type of care and supervision could be delivered in a different way, such as through community-based homemaker services, attendant care and home health care.

In short, it would be possible to individualize the dollars under the CAP. Established Programs Financing pulls apart the components of the care and funds them separately through CAP and through EPF. Only the CAP dollars could be provided, however, through an individualized route. A practical problem arises in that federal officials are not anxious to open up CAP any more than the program now allows; the current involvement of 50 percent funding is already considered to be a substantial contribution.

Education

Education at the primary and secondary levels is funded through provincial tax dollars. The federal contribution through the EPF arrangement described above does not apply; it is intended for post-secondary education only.

Because education at the primary and secondary levels is supposed to be universally available to all students — including those with disabilities — there should be no need (in theory at least) to individualize dollars for these services. In actual fact, however, children with disabilities have not had access to the educational services available to children without disabilities.

It is not likely that this problem will be resolved through individualized funding. Instead, it should be seen as a "systemic" problem which must be addressed by ensuring access by all to these publicly funded services. The recent legislative initiative in New Brunswick — Bill 85: An Act to Amend the Schools Act — is exemplary of the kind of change required to ensure the integration of children with special needs within the mainstream school system.

Individualized funding, however, may help address the problems which some families experience in trying to obtain support services in school settings. CAP explicitly precludes the funding of services considered to be primarily of an educational nature. If families were provided with funds, they could purchase the required services (as long as conditions under the CAP assistance provisions were respected). This represents only a short-term solution; ideally, support services should be part of a provincial/territorial program to integrate all students within existing educational services.

Vocational rehabilitation

Vocational rehabilitation services for persons with disabilities are funded primarily through the Vocational Rehabilitation of Disabled Persons (VRDP) Act. This Act allows the federal government to share 50 percent of eligible costs incurred by provinces and territories in the provision of vocational rehabilitation services.

VRDP shares in two types of costs: (1) the staff and administrative costs necessary for the provision of vocational rehabilitation services; and (2) the costs of specified goods necessary for the vocational rehabilitation of individual clients. Shareable costs are identified in the VRDP Act and Agreement.

While the Act allows for the cost-sharing of goods and services to individuals, these goods and services are not generally provided as dollars. They are usually provided as income-in-kind — that is, in the form of the actual goods and services themselves. However, a significant development in relation to the direct provision of dollars should be noted.

A Federal-Provincial Review of Fiscal Arrangements Affecting Persons with Disabilities was recently conducted. There were a number of important outcomes of this review, one of which was to allow federal support for the universal provision of technical aids and services to vocational rehabilitation clients. Another result was a consensus with respect to encouraging direct provincial payments to vocational rehabilitation clients for personal goods and services. In short, the VRDP Agreement now recognizes individualized funding for attendant care and for interpreters.

The outcome is significant because it explicitly endorses the concept of individualized funding for goods as well as for services. Governments appear willing to cost-share dollars provided directly to individuals for the purchase of vocationally related goods and services. This outcome is a critical step in the path toward the acceptance of individualized funding as a viable mode of providing support to persons with disabilities.

Housing

Assistance for housing costs is provided in one of two ways: (1) by supporting the supply of low-cost housing; and (2) by assisting individuals with the cost of housing.

In relation to the supply of housing, in particular, the Canada Mortgage and Housing Corporation (CMHC) shares, with its respective counterparts in the provinces and the Yukon Territory, in the costs of non-profit housing. (CMHC pays the full cost of non-profit housing in the Northwest Territories.) The dollars that flow under these programs are not directed toward individuals. Rather, they are directed toward the physical infrastructure of the housing project through mortgage assistance.

It would not make sense to consider the conversion of these funds to dollars for individuals because these funds fill a very important purpose in the housing market, i.e., they are intended to ensure an adequate supply of low-cost housing.

CMHC also shares, in conjunction with its respective provincial/territorial counterparts, in the cost of a Rent Supplement Program. Its purpose is to make available more low-cost housing by reducing the rental costs of a certain number of units in local communities throughout the country.

The program has been criticized, however, on the grounds that it ties the rent supplement to designated units rather than to the individuals who need the rental assistance. In effect, it attaches dollars to the required good (in this case, a housing unit). If for some reason the individual moves, then he or she loses the assistance. The supplement virtually locks individuals into their rent-supplemented units.

One of the possible ways of supporting the individual rather than the housing unit is to provide rental assistance to low-income renters as a refundable tax credit. The problem with this proposal is that it could be much more costly than the current program. There would likely be many low-income people who would qualify for supplementation (costs are now controlled by funding a limited number of rental units).

In theory, then, there is a way to individualize housing dollars. In practice, however, the option is unlikely unless the benefit is targeted toward very low-income households. In this way, the numbers of potentially eligible recipients could be kept down and costs more easily controlled.

It should be noted that housing assistance for welfare recipients, in particular, is already provided in the form of individualized dollars through the shelter component of the monthly welfare cheque.

Another type of "individualization" is embodied in the Residential Rehabilitation Assistance Program for the Disabled. This program makes available forgiveable loans to individuals to help them offset the costs of accessibility modifications to private residences. Because no assistance is provided under this program for actual housing costs (i.e., mortgage or rental costs), it is limited in terms of its relevance as a possible model for ongoing housing assistance.

Summary

It is difficult under current funding arrangements to individualize dollars for insured health care services because these are supported under a block-funded arrangement. It would be possible to individualize dollars for extended health care services provided in the form of long-term residential care only if the individuals are transferred into community settings. They would then become eligible for individualized dollars under CAP and for EPF block-funded health care services.

Educational services cannot be funded through individualized dollars, although there is a possibility of individualizing the dollars for the support services provided in schools. Ideally, however, these services should not be funded in this way. They should be part of an educational initiative which ensures the integration of all students in the mainstream school system by providing required support services.

There have been significant developments with respect to the individualization of funding for goods and services intended for the vocational rehabilitation of persons with disabilities.

Finally, housing dollars cannot be entirely individualized because most funding is directed toward ensuring an adequate supply of low-cost housing. The monies that are channelled into lowering the costs of rent could be redirected toward individuals rather than toward rental units. However, the potential cost of this form of individualization of housing assistance represents a major obstacle to the viability of this approach.

CONCLUSION

Individualized funding refers to the provision of funds directly to individuals to help them meet their basic and special needs. While this form of funding is essentially a variation of the existing welfare system, individualized funding can be a much more effective method of meeting the needs of persons with disabilities.

The Canada Assistance Plan is the primary mechanism in this country for financing the costs of social assistance (welfare) and of certain services. CAP can support a system of individualized funding, but only under its assistance provisions. These are the provisions that allow the flow of funds to individuals. These provisions also permit assistance to be provided in any form and for the compensation of both basic and special needs.

However, the assistance provisions require that certain conditions be met. Among the most important are that individuals must qualify for assistance on the basis of a needs test and that only prescribed services can be purchased. These must be purchased "by or at the request of a provincially approved agency".

The question of whether it is possible to individualize the dollars directed toward related services is not easy to answer. It would be possible, for example, to individualize the dollars intended for extended health care services but only by releasing individuals from institutional settings. In this way, they would be removed from the CAP/EPF interface and would be covered under CAP funding for certain needs and under EPF funding for health-related needs (funds under EPF cannot be individualized because they are provided by the federal government to provincial/territorial governments in the form of a block intended for the support of services only).

Finally, related services such as vocational rehabilitation can be funded in an individualized form while the support of other services such as education and housing cannot be easily individualized at all.

APPENDIX E

HISTORY OF THE IMPLEMENTATION OF SERVICE BROKERAGE AND INDIVIDUALIZED FUNDING

INTRODUCTION

Deinstitutionalization initiatives for people with a mental handicap and expansion of community support services were put on the policy agenda in British Columbia in the late 1970s. In implementing these initiatives, the provincial government made decisions about the planning and financial mechanisms to be used to manage deinstitutionalization. Service brokerage and individualized funding were proposed, and to some extent implemented, as one set of mechanisms for managing deinstitutionalization.

In the mid-1970s, just prior to the very early initiatives to begin downsizing institutions, British Columbia had approximately 1000 residents in Woodlands, 400 in Tranquille, and 300 in Glendale. These were large-scale facilities that provided the major source of care for people considered to have more severe mental handicaps.[1] In 1977, the B.C. Minister of Human Resources made the first commitment to begin moving individuals from institutional care to community alternatives. In 1981, the Government announced in the Speech from the Throne a "shift in emphasis" from institutional care to community supports. In 1983, a commitment was made to close the Tranquille institution in Kamloops. In 1986, procedures were established for downsizing the Woodlands institution on a ward-by-ward basis. Also in that year, the Ministry of Health established the Services to the Handicapped Division to develop community supports for individuals still living in institutional facilities and designated as "multiply handicapped".

The relationship between the critical phases in the implementation of deinstitutionalization, fixed point service brokerage and individualized funding are discussed in more detail below.

PROPOSAL FOR A *COMMUNITY LIVING PROGRAM* - 1977

In the 1960s and 1970s, approaches to supporting people with a mental handicap ranged from private family residences to group homes to large institutions. Community-based group homes and small-scale institutions provided care for anywhere between ten and fifty individuals, primarily those designated as having less severe handicaps. Large-scale institutions in British Columbia, which included the Woodlands School in New Westminster, Tranquille in Kamloops, and Glendale in Victoria, were the source of care for most people considered to have more severe mental handicaps.

Many parents of children with a mental handicap found that these institutions were the only source of care available. The only alternative was to provide twenty-four-hour care for their son or daughter themselves. This was not possible for many families, given commitments to other family members and to work. For many parents, institutional placement resulted in the break-up of their family, relinquishing daily contact and relationships with their family member, and relinquishing decision making to institution staff. It also resulted in an ongoing concern by many families that the institutional environment posed serious risks to the welfare and well-being of their son or daughter.

In January 1976, these parents had an opportunity to see and hear their private fears made public by Gunnar Dybwad, then a visiting professor at the University of British Columbia, and a world renowned expert in the field of mental handicap. Having spoken to professional staff and having toured the facility at Woodlands, Dybwad made clear his concerns about the conditions he observed in Woodlands. At a lecture that received front-page coverage in *The Vancouver Sun*, Dybwad maintained that:

> *Conditions at Woodlands School for the mentally handicapped are so bad, the school would be closed down and fined if it were a non-government institution ... How is it possible that in Woodlands you tolerate specific violations of the law which, if this were a private institution, would close down the institution? ... In the absence of adequate staffing, it's very hard to provide individual programs and to work out appropriate programs elsewhere ...This is largely not the fault of the institution but the community and the community agencies who reject these children ...*[2]

Dybwad's comments had a catalytic effect. Upon reading the press coverage of Dybwad's speech, one woman whose daughter was in Woodlands called the British Columbia Association for the Mentally Retarded (now the British Columbia Association for Community Living) to express her concern that "my child seems to be regressing instead of developing" in the institution. She asked that someone meet with her. Soon afterwards, a staff person and the chair of the Association who was herself the parent of a son living in Woodlands, visited the woman's home. With two other mothers present, the parents began to speak about their children, the experience of institutionalization, and their fears. Their sharing of experiences was emotional and difficult, but one that helped to carve out a space of mutual trust and support. The small group of parents continued to meet. The group grew substantially during 1976 as other parents were contacted and joined the group. It was during that year that they began calling themselves the Woodlands Parents' Group.

In sharing their personal experiences, the parents together developed a critique of the institution, and a set of principles they believed should guide the provision of supports to people with a mental handicap. Their critique reflected their perspective as parents. It was also, however, informed by the principles of "normalization" as developed in the work of Wolf Wolfensberger, and as shared with the group by one parent who had worked with Wolfensberger. The parents' guiding principles also reflected their expectations for their children which emerged through the sharing of experiences. Many of the parents felt that these expectations could not be met within what they saw as the restrictive and debilitating environment of the institution.

The three key aspects to the critique of institutions developed by the Woodlands Parents Group were: parent-child relationships; institutional restrictions on human development; and decision making within the institution.

First, the Woodlands Parents' Group found that relationships between parents and their children who were in Woodlands were affected by barriers that were integral to the institutional environment. The first of these was a lack of adequate parental access to their children. Children were, in many instances, situated in institutions or residences that were geographically distant from other family members. This made casual and frequent visits difficult or unlikely. The parents also viewed the ward system and the spatial organization of the institutional environment as being hostile and intimidating, not only to residents, but to visitors. Parents felt they were external and peripheral to the ongoing operation of Woodlands, having no meaningful place or role. Institutional arrangements effectively denied them the ordinary interactions that they felt should characterize family relationships.

Second, the Woodlands Parents' Group believed that the medical model of care informed the perspective and activities of many institution staff. The result, they believed, was a situation in which staff used medical diagnoses to label individuals with very limited — if any — abilities or human potential.

The physical and social concentration of individuals in the institution were presumed by families to inevitably lead to a social reinforcement of problems rather than to individual development. Patterning and modelling done within a "problem" environment was believed to reinforce problematic behaviours rather than encourage "normalizing" opportunities. Accordingly, many parents felt that their children had regressed in their social development since their institutional placement.

As the parents met and began to clarify their own values and principles, their outrage with the institution grew. They came to regard it as a setting that fundamentally undermined individual dignity, and that by its very nature denied their sons and daughters the opportunity to live and participate in the community.

Third, in addition to fostering estrangement between themselves and their children, parents felt that institutional services denied individuals and their families participation in decisions which would affect their lives. They perceived that parent input to decision-making processes was curtailed by the prominence of medical and bureaucratic authority. The bureaucratic nature of institutional organization and the formality of the institutional process made it difficult to deal directly and productively with institutional staff. The lines of accountability within the institution made it difficult for families to pin down those with authority and responsibility. Even when this was possible, parents were reluctant to express themselves because they felt that if they were to exert pressure on the institution, their children would be penalized.

As the Woodlands Parents' Group developed this critique they were also anxious to begin to address what they saw as unacceptable conditions in Woodlands. While they continued to meet as a support group, they also began to monitor conditions in the institution and to create a political force for change. In the first instance, they wanted to maintain a strong presence in the lives of their sons and daughters and to begin participating directly in decision making in the institution. In order to do this, the Group requested and received approval for parents to become involved in decision making at the ward level in staff or team meetings that concerned their sons or daughters. It was at this level that decisions were made that most immediately affected how care would be provided to individuals on a day-to-day basis. The group also sought the implementation of an "Abuse Procedure" by an independent body for dealing with parents' concerns or allegations of abuse. The group also sought the establishment of procedures for behaviour management; the development of individual programs; and representation on the Admissions Committee to Woodlands in order to stem admissions and continued investment in institutional care.[3]

Although involvement in decision making within the institution and the other action steps were seen as important interim measures, the Woodlands Parents Group believed the institution itself to be the fundamental problem. In their perception, the environment severely curtailed the possibilities, opportunity, and rights of their sons and daughters. They became convinced that the philosophy, environment and operational procedures of institutional care were in fundamental conflict with their beliefs, values and expectations for their children. The only real alternative, from the group's perspective, was to seek political commitment to develop community alternatives. In December 1976 they met with the Minister of Human Resources in B.C., then William Vander Zalm, who was the minister responsible for Woodlands and for policy concerning people with a mental handicap. The meeting resulted in an agreement that the Woodlands Parents' Group, with the support of the Minister, would pursue two goals:

- ongoing monitoring within Woodlands
- development of a community based system of services as an alternative to Woodlands.[4]

In order to achieve the first goal the group would continue meeting with staff at the ward-team level and seek ways of furthering their monitoring role within the institution. The second goal was to be achieved through the implementation of a proposal for a community-based alternative to institutional care. The proposal was to be submitted to the minister two months later, in February 1977. As a means of developing the proposal, a "Planning Group" was formed. The Planning Group was formed from a core group of parents from the Woodlands Parents' Group and a few visionaries and futurists who were to help them translate their beliefs and values into a set of mechanisms for providing community supports. The Planning Group made presentations concerning the proposal to a number of community organizations and agencies whose input and critique were sought and who were also represented on the Planning Group. While the Woodlands Parents' Group wanted a government commitment in favour of change, they also sought to develop a wider base of political support in the community through the Planning Group.

Entitled *Development of a Comprehensive Community-Based System of Service as an Alternative to Woodlands*, the proposal was submitted to the minister in February 1977. Revisions and more detailed plans were submitted in April and May 1977.[5] The basic principles of the community living board or fixed point of response, service brokerage, and individualized funding were articulated in this proposal. It stated that the Community Living Board (CLB) was to be mandated by the Minister of Human Resources to have two functions. First, the CLB was to act as an agent for the individual to develop a general service plan, and to act as a broker for the individual in obtaining services with the dollars that had been attached to the individual. Second, it would act as a back-up service for the community, assisting in research and development of needed community supports, and in the design of policy for community alternatives to institutions.

PROJECT LIFE - 1977-1981

In June, 1977, the Minister of Human Resources announced "Project LIFE" (Living Independently for Equality), expressing commitment to "a major effort to de-institutionalize services for the mentally handicapped".[6] The minister announced the establishment of the Community Living Board, and provided it with a mandate to play a central role in managing the deinstitutionalization effort. Within Project LIFE there was to be a multi-level role for the CLB in managing the process of deinstitutionalization within the province of British Columbia. The CLB was to play this role at the individual, organizational, administrative, and policy levels. At the individual level, the CLS was to "ensure integrated and appropriate community placement" and to "ensure that persons placed in the community program are not 'dumped' without suitable support". It was also to arrange for housing, employment, recreation, health services, protective services, and education. At the organizational level, it was to work with community service providers to foster resource development on the basis of individual "service programs". At the administrative level, it was to work with the Deputy Minister of Human Resources, and other deputies of the Social Services Committee of Cabinet, to ensure that necessary procedural and financial changes were made to "permit or enhance the community living concept". At the policy level, the CLB was to consult with the Deputy Minister of Human Resources, to ensure implementation of the policy. The Deputy Minister was, "on the basis of recommendations put forth by the CLB and CLB staff", to initiate policy change as required, in order to realize the goals of Project LIFE.[7]

The funding of the CLB was to reflect its central role in managing deinstitutionalization. The Project LIFE document, prepared by the ministry states that:

> *The CLB budget and all financial arrangements for the Community Living Program require approval of the Minister of Human Resources. The intent of the program will be to re-direct funds required for institutional care into the purchase of services for the mentally retarded individual at the community level.*[8]

The press release announcing Project LIFE and the establishment of the Community Living Board was more explicit on the funding for the CLB:

> *The Community Living Board will be established to assist with the development of local services and to arrange for placement of retarded persons from the various institutions. The program calls for the redirection of institutional funds into community services and up to $3.6 million could be available to the Board per year ... Vander Zalm explained that costs now average $18,000 annually to maintain a resident at Woodlands. "Our plan is to redirect those funds over a period of five or six years into community support programs."*[9]

In summary, management of the provincial program for deinstitutionalization was to be community-based or was to have a strong community-based component. A community-based agency was to be responsible for the transition planning for individuals living in institutions, and the initiative was to be funded at the same per capita level as that of institutional care.

Negotiations concerning the implementation of the Community Living Board under Project LIFE became an ongoing debate between the Woodland's Parents' Group and the government. On one hand, the Woodlands Parents Group insisted that the CLB be an autonomous, community-based, duly elected body. Formal registration of the Community Living Society under the Society Act of British Columbia was sought to ensure legal status for the Board as a separate and autonomous (i.e., non-government) mechanism.[10] On the other hand, the response by senior ministry officials to the minister's announcement of Project LIFE was to develop a plan for implementation of a Community Living Board where the board was to be appointed by the minister "partly on the recommendations" of various organizations, including the Woodlands Parents Group.[11]

Negotiations between the CLS and the government concerning the mechanisms for delivering financial and planning resources proceeded after the legal incorporation of the Society. Under the terms of the agreement, dated September 8, 1978, and signed by the Minister at that time, the purpose of the Community Living Society was and remains:

> *... to operate as a service broker through which institutionalized or potentially institutionalized developmentally disabled persons may be referred for service planning and placement in the community and to stimulate the development of community services to serve these persons.*[12]

Annual renewals of the grant for service brokerage continue within the terms of this same agreement. It states that the CLS is to carry out the following role:

> *To prepare and submit to the ministry annual estimates of the costs of General Service Plans in such form and at such times as the Minister requires.*
>
> *To prepare and submit for approval to the Minister a budget for each General Service Plan together with a strategy for the implementation.*
>
> *After approval of the General Service Plan and its budget to submit to the minister for approval an Individual Program Plan together with its costs.*
>
> *To assess, in collaboration with Institutional Facilities, those clients in the Institutional Facilities who may be suitable for participation in the Community Living Program.*
>
> *To prepare in collaboration with the client, Institutional Facilities, community service agencies and ministry officials, a General Service Plan for clients referred by the ministry indicating the goals and objectives for submission and approval by the minister.*[13]

The minister agreed:

> *Where the Society's administrative budget ... has been approved, to pay the agreed sum to the Society ...*
>
> *Where the Individual Program Plan has been approved, to purchase services on behalf of clients in accordance with the plan and participate with the Society in implementing the approved Individual Service Plan.*
>
> *To designate by name the Ministerial delegates who will act as liaison with the Society for the purposes of this Agreement.*[14]

The CLS received approximately $238,000 for core funding under Project LIFE for the first year of its operation in order to implement the Community Living Board and to employ contract service agents (or service brokers) to begin individual planning. By November 1979, twenty-four people had left the Woodlands School assisted by the planning resources of the CLB.

The implementation of Project LIFE by the CLS was hampered by a number of issues including: funding procedures and financial arrangements; contractual arrangements; the supply of community supports; and other implementation issues directly relating to brokerage.

Funding and financial arrangements

After the CLS had received the core grant for service brokerage under Project LIFE in 1978, it became apparent that the funding for purchase of services would fall short of the anticipated $18,000 per year per individual. As a result, part of the funding which the CLB had assumed would cover its own administrative costs, including brokers' salaries and training, had to be shifted to cover the purchase of services for individuals.

For the CLB, the levels of funding allocated were only one aspect of the funding issues that presented problems for the organization. At least as important was the challenge to remain consistent with the financial arrangements that in theory were to distinguish funding under Project LIFE from the usual practice of allocating dollars for community services. The agreement with the ministry stated that the Society would work with individuals, service agencies, institution staff, and the ministry to prepare General Service Plans for individuals. The allocation of dollars was to be contingent upon the provisions set forth in the individual's General Service Plan (GSP) and in the Individual Program Plans (IPPs) that were to guide implementation of the GSP. GSPs and IPPs were to be developed prior to individuals' actual transition to the community. GSPs were to be the bases of funding allocations negotiated between the CLB and the ministry for specific individuals. They were to be signed by the individuals prior to the ministry's purchase of services on behalf of individuals. IPPs were in turn to be the bases of contractual arrangements between individuals and the specific providers of components (services) of the General Service Plan. Individualized funding was to be achieved by the ministry's allocation of dollars on the basis of individual need and as reflected in the GSP. Contractual status was to be provided to individuals in their negotiations with service providers. These negotiations were to culminate in service purchasing agreements that reflected the individuals' status, desires, and interests. For some of the families involved in the CLS, this funding procedure was viewed as a significant operational shift that had the potential to increase individuals' autonomy and decision-making capacity in service decisions. If individuals could make decisions about where and for what purpose dollars would be allocated, and if services were actually available for purchase, a significant measure of consumer purchasing power could be achieved in the realm of social services through the portability that the new arrangements promised.

However, as the organization began to negotiate with the provincial government for individualized funding, the funding process that had been originally conceived began to break down in its earliest stages. As one of the original agents recounts:

> *So here we have this regional manager who was attempting to cooperate with this new agency on the block, didn't know how to individualize dollars, so frequently in those initial meetings he would pick up the phone and phone Victoria and ask, "How would we do this, how would we individualize dollars? What did it mean? How would it fit in with the guidelines that were there?" He didn't get answers. But he did negotiate with us anyway.*

While it was implied in the mandate of the CLB that mechanisms for distributing individualized funding would be established, for a variety of reasons these mechanisms never fully materialized. Some people have maintained that there was never any solid commitment on behalf of some officials in the ministry to change the mechanisms for allocating funding in ways that dollars would "follow the individual" from the institution, through the Community Living Board, into purchase of services. Others point to reticence on the part of service providers to enter into such "revisionist" arrangements for funding and service delivery.

Contractual arrangements

Because these mechanisms were not effectively implemented in the early stages of Project LIFE, the role for the CLB in acting as an agent for the individual in ongoing service delivery became problematic. By late 1978, the service brokers, or service contract agents as they were then called, were already finding that they could not make effective interventions on behalf of individuals.

In many instances this occurred because service providers simply refused to enter into contractual arrangements with individuals. This situation arose largely because conventional funding mechanisms tied dollars to services in such a way that the revenues, and therefore the operational capacities of service providers, did not depend significantly on the financial resources that were to be supplied through the CLB in accordance with individualized service purchase contracts. Yet the preparedness of service providers to enter into these contracts was vital to the functioning of brokers as originally conceived. The role of the broker, as the individual's agent with a mandate to ensure compliance with the terms of the contract, was legitimized precisely through the individual service contract or "written understanding"[15] between service provider and the individual requiring service. The discretionary power of service providers to refuse to enter into these contracts, then, effectively circumscribed the broker's role in the realm of social services, a procedural problem that has continued to hamper the implementation of service brokerage. It has also curtailed the contractual status of the individual with a mental handicap in relation to the service system.

Development of services

In the implementation of Project LIFE, there were also many difficulties concerning the supports that individuals received. Some individuals had acute social and emotional needs in addition to a mental handicap, which made designing and creating provisions for their initial community living arrangements problematic. Sometimes the arrangements that were made were entirely inadequate.

Some of the first referrals from Woodlands were made under considerable time constraints. In many instances, time factors accelerated the planning process to the point of rushing it for individuals whose needs required considerable planning effort.

Further, Woodlands did not in these early stages make available to the CLS the names of the 200 individuals which the ministry had indicated were most ready to move to the community.[16] Consequently, it became difficult for brokers to predict and develop proactive contingency plans for service needs in advance of individuals' actual transition to the community.

As well, conventional services were not readily available for all the individuals for whom the CLB was brokering. When residential services could be located, they were frequently found to be inadequate or inappropriate to the individual's needs. The lack of appropriate support services in the community led to disruptive crisis situations for some of the individuals.

Similarly, some of the local Associations for the Mentally Retarded, as they were then called, who provided the bulk of existing community services, had long waiting lists and did not have experience in supporting individuals with extremely challenging needs. Given these reasons and their reluctance to enter new arrangements that required the involvement of a service broker, association-run services did not appear to be feasible options for many individuals involved with the CLB.

As a result of these supply factors, the CLS was required to devote extensive time to developing alternative resources in order that individuals could be supported in the community.

The powers of service brokers

Another issue that surfaced during the initial Project LIFE phase concerned the responsibilities and powers of the service contract agent, or broker. The number of brokers varied, at one time expanding to twelve. Many of these people had previous experience as Adult Protective Service Workers in Ontario. The Community Living Board had presumed that families would be actively involved in the community placement of their sons or daughters, thereby fulfilling an advocacy role and helping to make decisions regarding the services individuals would use. Because the first individuals were mostly persons without actively involved family members, and because brokers had become frustrated with the social service system's inexperience with and resistance to community living for these individuals, the brokers increasingly stepped beyond an information-generating, consultative, and mediating role. They increasingly took on an active decision-making role for individuals. This occurred even where families were involved. As one broker recalls:

> *In those first three years we did not have a sense that it was really important to make darn sure that it was the*

> *family's [role to do the] decision making around the individual. We really did assume almost complete responsibility for decision making ... We didn't have a sense of the urgency and priority, that it was critical for those folks to have somebody who wasn't paid to be there, to help them in their decision-making process ... So the broker would make the arrangements and even contract with the people who were paid to support the individual.*

Some parents who were actively involved with the CLB saw brokers as usurping parents' legitimate role and they became alienated from brokers as a result. Government and community agencies who sometimes perceived brokers' demands and their approach as unreasonable also became alienated. Members of the CLB stressed that an advocacy role by brokers would not necessarily ensure the delivery of adequate services when what was needed was information and planning assistance.

Key issues regarding the nature and extent of brokers' involvement in planning and decision making for individuals were raised during the early stages of implementing the model. Parents, government and service providers were concerned about how brokers were exercising their functions. In addition, limitations on the funding of brokerage led to a variation in the number of brokers. These factors made it difficult for brokers to be intensely involved with individuals on an ongoing basis. For these and other reasons the CLB reaffirmed at this stage of its history that brokers' role should be limited to that of a technical support.

The CLS did recognize that, where individuals did not have family members who could be involved in the planning, some other form of personal support involvement was needed. In coming to this conclusion the CLS in effect confirmed that families were to function as the primary, if sometimes scarce, source of advocacy for all individuals.

Project LIFE was conceived as a strategy for managing deinstitutionalization that had implications at the policy, administration, organization, and individual levels. On all of these levels, however, the Project began to falter soon after its initiation.

As a policy initiative, the Project required funding levels and new financial arrangements which, although committed by the Minister of Human Resources, were not forthcoming to the extent originally anticipated by the CLS.

As an administrative strategy, the Project was to have developed collaborative relationships among the CLS, ministry staff, institution staff, and community service providers, in order that community supports would be developed and the transition from institution to community could be carried out. The varied interests and philosophical positions at play made collaboration an elusive goal.

As an organizational strategy, the Project required that the CLS have a clear sense of the planning supports that it was going to make available to individuals and their families. It also required that the organization have a clear understanding of how to deliver those supports in a manner consistent with the stated ideals, and a strong capacity to do so. The CLS was not fully able to deliver the service brokerage role in this early stage. This was due to a number of factors. Financial and community service resources were strained to the limit. Individuals had extremely challenging needs that again strained the capacity and willingness of existing services to fulfil their role. Individuals often lacked personal supports to participate in and guide the planning. And in the context of this environment, brokers stepped beyond the boundaries of the role that had been defined for them.

The real impact of these factors became most visible at the individual level. Often the only accommodation that could be found for individuals with extremely challenging needs were inadequate boarding homes, without appropriate or adequately trained support staff.

The beginning of the CLS service agency - 1980-81

In 1980, the CLS made the decision to begin delivering residential support services to individuals moving from Woodlands. This was a significant departure from their mandate under Project LIFE to act exclusively as an autonomous fixed point of response.

A number of factors led to the decision to begin delivering services directly. The most urgent and pressing factor was that by the summer of 1980, many individuals who had moved to the community with the support of the CLB were living in conditions that had become entirely inadequate and completely unacceptable from the perspective of some of the families and the staff with the CLB. Further, there was no funding for the individuals who were living in Woodlands and with whom brokers had been meeting to prepare for the move to the community. As a result, these individuals and their families appeared to have been put indefinitely on hold. There were corresponding pressures on the organization to remedy the situation.

These problems were compounded by the fact that the organization was in a financial and organizational crisis of its own with little funding to remedy the situation. Contributing to the financial and organizational crises were inadequate cash flow, inadequate funding from the ministry, and management issues. There were also questions about whether support staff hired by the CLB were employees of the agency and therefore entitled to employee benefits, which would have meant significant expenditures for the organization, or whether employees were actually privately contracted "free agents" of the individuals they supported. By the end of August of that year and in the midst of these serious problems, the organization found itself without sufficient funds to pay the staff, support workers, or rents for individuals being served. The organization's bank credit limit had also been exceeded.

At this time, consideration was given to the idea that the CLS incorporate a separate "Community Living Residential Society", and enter into contracts with the ministry to deliver residential services. The CLS would be maintained as an autonomous fixed point providing service brokerage. A draft constitution was prepared in September 1980 for the residential agency, but the separation of the fixed point of response and the service agency was not given detailed consideration at this time. This was due, in part, to the fact that the situation required as immediate a response as possible. As well, some of those involved with the organization believed that such a move would have spelled the end of service brokerage. It was already evident by the summer of 1980 that service brokerage did not fit easily into the existing service system. There was a fear on the part of some of those involved in the CLS, therefore, that the contract and grant for service brokerage would eventually be cancelled if brokerage was not attached to a service mechanism, such as a residential service agency, that had greater status in the eyes of government and the social service system generally. It was postulated that the CLS Board could still function as the planning and information vehicle for individuals and families served by CLS residential services. Because the CLS seemed compelled to build a community service system that would in all likelihood not be based on the individualized funding and contractual arrangements that had been envisioned under Project LIFE, the Board began to inch towards delivering both brokerage and residential services. It did so partly in the interests of not losing service brokerage entirely.

After the government supplied interim funding to deal with the immediate crises, negotiations began in the fall of 1980 with the Ministry of Human Resources. The Minister of Human Resources, then Grace McCarthy, had indicated that the CLS would not be receiving "additional clients" from Woodlands until arrangements for delivery of services to "current clients" had been clarified. As there were no other community service agencies in the Lower Mainland willing to accept individuals with challenging needs from Woodlands, and because it was clearly imperative to remedy the situation for individuals then served by the CLS, the CLS concluded that it had little alternative but to begin providing its own residential services. By the end of that fiscal year, the CLS had entered block-funded contracts to begin delivering those services.

Under this arrangement, funding was not to be allocated under Project LIFE but under the regular provisions for funding of community residential services. Accordingly, individualized funding arrangements were not used. It was agreed, however, that the CLS would negotiate contracts for its residential and vocational services on the basis of individually costed general service plans, thereby maintaining one element of an individualized funding model. While the procedure would not give individuals contractual status, it would ensure in theory if not in practice that funding was "attached" to individuals.

In order to implement these unique arrangements it was agreed that all negotiations and funding would flow through one regional office of the ministry, even though the services that the CLS delivered to individuals were to be located in a number of regions of the ministry. These arrangements have continued up to the present.

From all perspectives the decision by the CLS to deliver residential services, and the decision by the ministry to expand funding, did create the conditions for realizing the initiative to bring more individuals from Woodlands to the community. The Government of British Columbia re-affirmed and strengthened its commitment to deinstitutionalization later that year (November 1981) in the Lieutenant Governor's Speech from the Throne:

> *My government recently has developed a new approach for the care of the mentally handicapped. This involves a shift in emphasis from care in large institutions to a range of community-based options. It builds upon the progress that has been made in developing a co-ordinated Government approach to service delivery.*[17]

Having made a decision to close institutions in the province and increase funding for community supports, the ministry stepped up its plans to move individuals from institutions to the community. Residential service provision by the Community Living Society, and soon afterwards CLS vocational and other day programs, grew substantially in the 1980s as the ministry looked to the Society to plan for and serve those individuals in Woodlands with particularly challenging needs.

The decision by the CLS to deliver residential and day services was made in the midst of a complexity of forces — financial necessity, a pervasive sense of crisis about the organization, a deep concern for the individuals it served, a solid commitment to assist individuals to move from the institution to the community, and fear about the fate of brokerage. A few of those affiliated with the organization opposed the move. All of those involved found the decision an unfortunate but necessary compromise from the original ideal of an autonomous fixed point of response. To those on the Board and in the administration of the organization, the decision appeared to be the only way that services could be secured in the community for individuals in Woodlands, and the only way that service brokerage, albeit a compromised service brokerage, would survive. To say the CLS was reluctant to make the decision is to miss the reality of the pressure the organization was under. To say they were forced into the decision would be too strong.

Nonetheless, the decision to deliver brokerage along with a variety of other services did signal an important compromise of the mandate of the CLS to act as a fixed point and planning support, autonomous from both the funding agency and service providers. The contradictory forces that would underscore the organization's future were firmly cast with this decision.

For instance, as the CLS clarified and refined on a conceptual level the mechanisms of autonomous service brokerage and individualized funding, the policy environment and the demands of deinstitutionalization entrenched the organization more deeply as a service provider. The implications of the compromise figured most sharply, perhaps, in the altered status of the individual's General Service Plan. Under the 1978 agreement, the GSP was to be the basis on which funding was to be allocated and services purchased. Although from late 1980 onwards the CLS and the government continued to negotiate funding for service provision on the basis of the GSP, negotiations could only begin when it was agreed that CLS would be the service provider. A GSP only came into existence if the CLS was able to deliver services. An agreement with a predetermined service provider of residential and vocational services, in effect, came to supersede the GSP. If the GSP no longer served as an agreement between the individual and the funder for the services to be purchased, neither did it facilitate choice in the service providers to be used.

Other assessments of the success of Project LIFE, and of the mandate and success of the Community Living Society under this initiative, vary depending on the perspective taken. By mid-1981 the press, some members in the B.C. Legislature and the British Columbia Association for the Mentally Retarded were claiming Project LIFE to be a failure. The claim was based on the argument that the initiative had not led to substantial numbers of individuals moving from the institution to the community. This side of the debate was played out in the Legislature in June 1981 beginning with questions from the Member from Surrey. In response, the Minister of Human Resources pointed to the fact that the CLS had received a massive increase in financial resources for service delivery, and that this could be taken as evidence that Project LIFE was indeed a success.[18]

THE CLOSURE OF THE TRANQUILLE INSTITUTION - 1983-85

In 1983, the government again committed itself to deinstitutionalization by announcing that the Tranquille institution in Kamloops would be closed over an eighteen-month period. As with the implementation of Project LIFE, the government had to choose the financial and planning mechanisms by which the deinstitutionalization process would be managed.

The implementation of the Tranquille closure marked a definite shift in the mechanism for allocating planning resources. An autonomous, community-based, community board was not chosen as the planning mechanism. Instead, the ministry pursued a decentralized strategy in which the planning function for individuals moving from Tranquille would be located within the regional offices of the ministry, and within local Associations for the Mentally Retarded, most of which were providing either residential supports, day programs or other services. "Project teams" were formed within the ministry's regional offices to manage individual planning and resource development. They were to work in conjunction with "resource developers". The resource developers were hired by the regional offices of the ministry and attached to local associations within a given region. The resource developers and the planning process that were put in place for the closure of Tranquille were seen by some senior officials in the ministry to make redundant the delivery of service brokerage through the CLS. In a memorandum to the Board, representatives of the CLS who had met with senior officials reported:

> *... there does not appear to be a role in the near term for the*

> *CLS brokerage service. This is due to the fact that, as a result of the Tranquille project, the ministry now has on staff a Project Team that is responsible for providing this service within the ministry. MHR [Ministry of Human Resources] suggests that the CLS Directors may wish to re-evaluate the CLS budget allocation for this service and redirect a portion to other Society needs.*[19]

Despite the emphasis on retaining the planning function within the ministry and to some extent within local associations, the ministry did contract the CLS to provide service brokerage to twenty-five individuals moving from Tranquille. The GSPs developed by brokers were to be used to inform planning and service provision on a concrete level. The GSPs were also to be used in funding negotiations between the ministry and four service providers the ministry had designated to provide residential and vocational supports.

From the outset, the CLS was much firmer than it had been under Project LIFE about having its role as agent for the individual recognized in contracted arrangements with the service providers, and about individual service contracts guiding the allocation of funding to the service providers. The CLS did secure a measure of status in contract relations with service providers through letters of understanding to which the providers became signatories on a voluntary basis. The letters also included provisions for the CLS to assist in resource development, staff training, and the design of a monitoring function. The ministry held back, however, on giving formal status to the General Service Plans as instruments outlining the terms of, and directing, service delivery. Similarly, apart from the terms within the voluntary letters of understanding, the role of service brokers as planning agents for individuals was given no further formal recognition. Further, the contractual status of the individual with a mental handicap who required service was not formally recognized. Instead, accountability of the service provider to the funding agency was secured through the purchase of service agreement between the ministry and the four designated providers.

It is clear that, while service brokerage did not come to an end, the scope of its effective activity had been further restricted during the Tranquille closure. Brokers were not able to effectively continue their role as the individuals' agents after finalizing service arrangements and during the implementation of the service contracts.[20]

TENDERING PROCEDURES FOR THE CLOSING OF WOODLANDS

The Tranquille institution was closed in 1985. In 1986, the Ministry of Social Services and Housing (previously named Ministry of Human Resources) designed procedures to begin closing the Woodlands School on a ward-by-ward basis. The strategy chosen for the downsizing of Woodlands was much more centralized than had been the case during the Tranquille closure. That downsizing is currently under way.

As was the case with Tranquille, a tendering process is used for the selection of service providers. Ministry social workers based at Woodlands, together with ward staff, prepare "non-identifying profiles" of individuals. The profiles of a cluster of individuals, whom ward staff have determined will live together, are then sent out to prospective residential and vocational service providers. The providers prepare service delivery proposals, and submit to the ministry bids to serve the clusters of individuals. Senior staff in Woodlands and from the ministry review the proposals and sign contracts with the selected service providers.

The procedures clearly locate the individual planning function within the ministry. Current arrangements do not include mechanisms for allocating dollars according to individual need, nor do they provide for the contractual status of individuals with a mental handicap in service delivery agreements. The ministry document that describes the tendering procedures for community placements, or "transition planning", indicates that parents will not be involved in the selection of service providers. They are to be advised when the decisions have been made.[21] Accordingly, opportunities are minimal for individuals and families to define their own goals for living in the community, to determine their needs for support, and to participate in negotiations with providers about who can best meet these needs.

In many respects, current procedures for managing the closure of Woodlands represent the end point in a long-term policy drift away from the principles that originally were the basis of the Project LIFE policy.

ESTABLISHMENT OF SERVICES TO THE HANDICAPPED DIVISION, MINISTRY OF HEALTH - 1986

The Ministry of Health established the Services to the Handicapped Division to develop and fund community-based services for individuals with multiple handicaps who require extended care services.[22] This initiative was part of the overall deinstitutionalization policy of the government. The Ministry of Health has been given financial and planning responsibility for a number of individuals who are deemed to have multiple handicaps, now living in Woodlands, in the Glendale institution, and in smaller facilities. As the Ministry of Health does not have in-house planning resources to manage the process of community placement, it has contracted with independent planning agents, including CLS brokers. In these cases, funds have been allocated on the basis of individual plans, in accordance with the CLS model.

The Ministry of Health currently lacks an overall strategy to carry out the planning function. While there have been some proposals within the ministry to utilize service brokerage as a more widely used mechanism for allocating planning resources, these have not been implemented.

REORGANIZATION OF THE MINISTRY OF SOCIAL SERVICES AND HOUSING

In 1988, the Ministry of Social Services and Housing announced a plan to reorganize the delivery of its services in order "to more effectively direct our resources to meet the changing needs".[23] One of the changing needs the ministry identified, that served as a rationale for the reorganization, was the increasing numbers of individuals with a mental handicap who were moving from their family home or institutions into community-based support services. The ministry projected an increase in these individuals from 1,995 in the year 1986-87 to 2,754 by 1989-90.[24]

The response by the ministry to this projected increase in demand for planning services was to establish a specialized division, Services to the Mentally Handicapped. This division delivers the planning assistance that individuals require to arrange community supports and services. In many ways, this development signifies the final demise of the notions of an autonomous planning support mechanism, together with contractual status for the individual and individualized funding, that were, through Project LIFE, to provide tools for the empowerment of individuals with a mental handicap and their families.

CURRENT ACTIVITIES OF THE CLS

Although this historical discussion has indicated a progressive abatement in the implementation of fixed point service brokerage and individualized funding, the CLS continues to operate as a community-based fixed point of response. Service brokers continue to provide planning supports to individuals moving into community arrangements from the institution, from their family home, or from another service setting. As well, the CLS continues to mediate between individuals and service providers, and to facilitate the development of services as requested. Although service brokers are not entirely autonomous from CLS service delivery, they do prepare general service plans with individuals, and assist in negotiating costs with the ministry on the basis of these plans. This is done with the recognition that CLS will be the residential and vocational provider. Some contracts with the Ministry of Health have provided opportunity for more "pure" service brokerage and individualized funding.

* * *

This examination of the history of the implementation of service brokerage and individualized funding can be summarized, in part, by an overview of public records and documentation on the Community Living Society.

The commitment to the funding and concept of the community living board, to be implemented by the CLS, was reflected in the late 1970s in the *Public Accounts* of British Columbia. Project LIFE, the program which provided funding for the CLS to carry out service brokerage, and to provide assistance in individual service contracting, was given a separate budgetary line. In the "Accounts", the purpose of allocations under "Living Independently for Equality" (Project LIFE) was to:

> *Provide(s) services to community living boards to assist handicapped persons in institutions to move to the community in order to live as independently as possible.*[25]

After 1980, however, Project LIFE was no longer entered as a separate budgetary item in the ministry's accounts. The program was never publicly cancelled, but the loss of a separate budgetary line for allocations to community living boards corresponds with the changing status of the Community Living Society in the 1980s as a major residential and vocational service provider. The cancellation of Project LIFE as a separate budgetary item was one sign that its implementation, as a particular set of financial and administrative arrangements, was no longer a government commitment. Funding allocations to service providers rather than to the plans of individuals (as with GSPs), was to become the mechanism for delivering financial resources to people with a mental handicap.

However, there continued to be some recognition within the Ministry of Human Resources (later termed Ministry of Social Services and Housing), that the government would purchase planning services on behalf of individuals from the CLS, as a community-based agency. The recognition that the CLS was to continue to provide assistance in general service planning is reflected in the annual reports of the ministry. Each of the annual reports, from the years 1978 through 1985, provide a separate entry for the CLS. The reports provide similar descriptions of the function of the CLS:

> *The Community Living Society is a non-profit society from which the ministry purchases services to assist with the orderly planning and community placement of developmentally disabled persons who are, or were, residents of Woodlands. In addition, the society encourages present community programs to serve these people and assists in developing new resources where required.*
>
> *The society works with an individual, his/her family, and ministry staff, to identify needs, develop and implement a plan, and co-ordinate the services required to ensure the well-being and continued growth of the handicapped person ...*[26]

The entry on the Community Living Society does not appear in the annual reports after 1985. This shift in the official status of the CLS and community-based planning for individuals corresponds with a shift in ministry policy. In 1986, the ministry began implementation of the plan to close the Woodlands School on a ward-by-ward basis, and to move individuals to community settings. Transition planning for individuals was located within the ministry and the institution. In 1988, the ministry announced a reorganization which created a specialized division within the ministry to provide planning assistance to individuals with a mental handicap. In many ways, the reorganization suggests the demise of the principles for planning and funding mechanisms on which the proposal of the Woodlands Parents Group and Project LIFE were based.

Notes

[1] British Columbia, Ministry of Human Resources, *Annual Report 1976* (Victoria: Office of the Minister of Human Resources, April, 1977).

[2] In "Conditions at Woodlands 'so bad school should close' ", *The Vancouver Sun*, Friday January 23, 1976.

[3] The Woodlands Parents Group, *Development of a Comprehensive Community-Based System of Service as an Alternative to Woodlands*, Presentation to the Minister of Human Resources by the Woodlands Parents Group (Vancouver: February 1977).

[4] In letter from Ingo Rampre, Woodlands Parents Group, to The Honourable William Vander Zalm, Minister of Human Resources, February 24, 1977.

[5] The Woodlands Parents Group, *Development of a Comprehensive Community-Based System of Service as an Alternative to Woodlands*.

[6] British Columbia, Department of Human Resources, *L.I.F.E. Living Independently for Equality* (Victoria: 1977).

[7] *Ibid*.

[8] *Ibid*.

[9] British Columbia, British Columbia Government Press Release, *Subject: PROJECT LIFE*, Issued by the Minister of Human Resources, June 11, 1977.

[10] The Society was formally registered on January 16, 1978.

[11] British Columbia, Ministry of Human Resources, *L.I.F.E. Living Independently For Equality* (Victoria: 1977).

[12] British Columbia, *Agreement between the Community Living Society and The Minister of Human Resources*, September 8, 1978.

[13] *Ibid*.

[14] *Ibid*.

[15] Discussed in Community Living Society, "Situation Report: 23rd November 78 - Policy Issues" (Vancouver: November 1978).

[16] These issues are discussed in Community Living Society, "Work-

ing Relationships: A Period of Working Out the 'Bugs'", a document prepared for a meeting with the Minister of Human Resources, May 8, 1978 (Vancouver).

[17] British Columbia, Legislative Assembly of British Columbia, *Votes and Proceedings of the Legislative Assembly of British Columbia* (Victoria: November 23, 1981).

[18] British Columbia, British Columbia Legislature, *Hansard*, June 2, 1981.

[19] This statement is made in a memorandum to the CLS Board of Directors, dated March 7, 1985.

[20] Community Living Society, *Summary Table of Progress to September 27, 1984 for Tranquille Project* (Vancouver: 1984).

[21] British Columbia, Ministry of Social Services and Housing, *From Institution to Community: Parent Involvement in Community Placement Planning* (Victoria: January 1987), p. 5.

[22] British Columbia, Ministry of Health, *An Overview of the Services to the Handicapped Division of the Ministry of Health* (Victoria: November 5, 1987).

[23] British Columbia, Ministry of Social Services and Housing, *Information Package: Ministry of Social Services and Housing Reorganization* (Victoria: Corporate Services Division, April 8, 1988).

[24] *Ibid.*

[25] Allocations for the core grant for service brokerage were provided under Project LIFE for the fiscal years ending 1979 and 1980. In subsequent years the agreement for service brokerage has been funded under different budgetary lines within the Ministry's accounts. See British Columbia, *Public Accounts of British Columbia For the fiscal year ending March 31, 1979, Volume 1 - Financial Statements* (Victoria: Ministry of Finance, January 31, 1980), *Vote 155; British Columbia, Public Accounts of British Columbia For the fiscal year ending March 31, 1980, Volume 1 - Financial Statements* (Victoria: Ministry of Finance, September 30, 1980), Vote 144.

[26] *Ibid.*

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